



Trustees' Annual Report & Accounts

2017





DEBRA

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Report & Accounts

Together, we #FightEB.

DEBRA embarked on its first integrated appeal and campaign in 2017, utilising both traditional and digital marketing methods.

This was the beginning of the #FightEB movement.



Heather's Story

Overcoming adversity...

If you've ever worn a new pair of shoes, walked a few miles in tight boots or scalded yourself on a hot kettle, then chances are, you know what it's like to get a blister. It causes a bit of discomfort and inconvenience while it heals, then it's often forgotten. For Heather, the experience couldn't be more different.

A single blister can leave Heather unable to walk. She suffers from EB, which causes her skin to blister and tear, leaving her in excruciating pain. Everyday activities, like standing, walking and even holding a pen, can give Heather agonising blisters.

Sometimes the pain is so bad she crawls on the floor to take the pressure off her feet. 'The most frustrating thing about EB is the pain. There's nothing you can do to get away from it. It's hard to make others understand what it's really like,' she says. 'I don't talk about it anymore because it's part of my everyday life.'

Heather doesn't let her EB stop her from doing anything. She's the first woman in the world to qualify as a tank paintball instructor, a physically demanding role that many people would think twice about. But Heather is fearless - she's also the only woman in the world eligible to run a tank paintball battle.

Life with EB can be very isolating. Through DEBRA, Heather has been able to meet other people suffering from EB and share experiences, something which makes a huge difference to her quality of life. 'Growing up, I was often the first person with EB that doctors and nurses had seen. It was a very lonely experience. DEBRA's always been there for me, providing a support network whenever it's needed.'



WHAT DOES DEBRA DO?

DEBRA is the national charity supporting those directly affected by, and working with EB (Epidermolysis Bullosa) – providing lifelong support to the entire EB Community.

Working as a team to understand the needs of the entire EB community underpins DEBRA's core strategy. DEBRA offers practical, financial and emotional support to, and advocates for, EB sufferers; partners with the NHS to provide specialist care and internationally-recognised clinical care guidelines; and works with researchers investigating alleviation for the debilitating effects of living with EB.

DEBRA has achieved global recognition as a leader on EB, and is the only charity specifically aimed at continuously supporting the EB Community network. Investing more funds and increasing the number of dedicated people allows DEBRA to share knowledge, skills and experience to empower and enable achievements within the Community. Expanding and strengthening family health and community support networks to improve quality of care is vital to DEBRA's work.

Supporting DEBRA – be it through fundraising efforts, direct donations, purchasing items in the retail shops or offering your time as a volunteer – has a direct impact on helping the EB community.

DEBRA envisages a future when no one suffers from EB. Until then, DEBRA strives to improve the quality of life for the EB Community.

WHAT IS EB?

EB is a potentially fatal skin condition that causes constant pain due to unstoppable internal and external blistering.

There are an estimated 500,000 people suffering from EB worldwide, and one in 227 of us carry a defective gene that could cause the condition.

In its most severe forms, EB is fatal; even in its mildest forms it can still cause lifelong disability and pain. Blisters continuously form and have to be drained and dressed daily, which is a painful process that can take several hours.

The building up of scar tissue from repeated blistering can cause fingers and toes to fuse together, which can also lead to an aggressive form of skin cancer. The overall impact of EB affects the whole body and psychological challenges are inevitable.

EB is currently incurable.



Ayaan's Story

Living life like everyone else...

Every week thousands of kids walk to school; for 10-year-old Ayaan, this short journey is impossible.

Ayaan loves meeting up with his friends, travelling to new places and trying new things. However, even walking short distances causes terrible damage to his skin, so staying active with his friends is a real challenge. Ayaan suffers from EB, which causes the skin to blister and tear at the slightest touch and leaves behind open wounds.

Sometimes, EB causes so much pain that he is unable to walk. 'It breaks my heart that Ayaan can't take part in activities that other children take for granted, like playing football and walking to school,' says his mum, Tayiba. 'He gets so frustrated, he'll say 'I hate myself; I don't like my skin'. I feel so guilty.'

Care and support from DEBRA helps Ayaan look after his skin, so he can spend more time with his friends. Specialist EB nurses, part-funded by DEBRA, showed Ayaan how to dress his blisters and what creams to apply to encourage healing. And through DEBRA's Members' Weekend and other events Ayaan and his family have been able to meet others suffering from the condition.

'I never imagined I'd meet so many other people suffering from EB. The support from DEBRA has been amazing - knowing they are able to help whenever we need it has made such a huge difference to our lives,' says Tayiba.

EB is always there. On-going research provides real hope for effective treatments and a cure for EB. Until then, Ayaan has no other option but to learn how to cope with the debilitating pain. 'I'd love to make EB disappear,' says Tayiba, 'That's why it's important to keep funding research into this condition.'

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#FightEB



Heather & Wendy's Story

On a mission to stamp out EB...

You've worked your way through college. You've got yourself a job. And you're making plans to move into your own place. Then you're diagnosed with cancer and all your plans get put on hold. For 27-year-old Heather, that's exactly what happened.

Heather is a five-time cancer survivor. She's had numerous operations to deal with internal injuries. She's blind in one eye. Hospital visits and painful daily bandage changes are simply part of everyday life for her and her mum, Wendy.

All because she has a skin condition - Heather suffers from EB. The cancer is caused by her EB. It's aggressive and almost certain to come back. But she doesn't let anything get in her way.

'I have EB, but EB is not me. Yes, I have good days and bad days, but you can't sit around thinking 'I might die today'. You have to get out and enjoy life,' she says.

OUR WORK

IN 2017



For every £1 raised 81p was spent on charitable activities



£3,299k spent on charitable activities in 2017



£1,570k raised in DEBRA shops and **£1,324k** by DEBRA fundraisers



34,000 active registered Gift Aid donors

Research

10 research projects were facilitated in the UK

£1,275k committed to new research projects

c200 members involved in an online patient research panel

Healthcare

2,000 patients supported by EB specialists

26 specialist EB training grants

Up to 25% of specialist EB nurses costs covered by DEBRA

Community Support

2,640 DEBRA Members; 505 of which accessed DEBRA's Community Support service

378 home visits took place; 111 EB hospital clinics attended; and 233 support grants were awarded

630 holiday days taken in DEBRA's five holiday homes

International

56 DEBRA groups worldwide

2 international clinical best practice guidelines, funded by the UK

30 global EB research sites



Beata's Story

Raising awareness in the medical community...

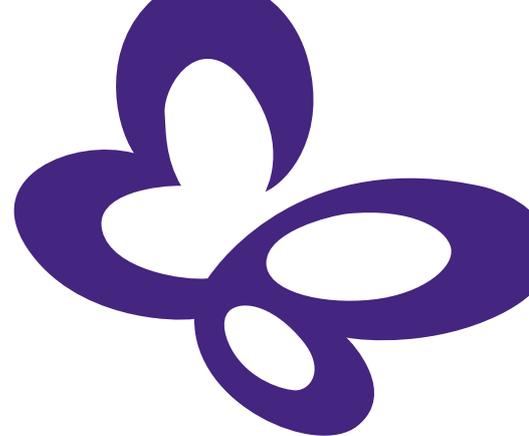
When you're expecting your first child, people always say your life will change forever. Beata, who worked as a nurse at a London hospital, didn't realise how true this was until her son, James, was born.

The skin was missing from both of James' legs. 'He was in so much pain. He couldn't feed. He was crying so much and we couldn't console him,' Beata remembers. Doctors confirmed that James had EB. In spite of her medical training, Beata knew nothing about EB.

The following weeks passed in a whirlwind of shock. With support from specialist EB nurses, Beata learned how to look after his skin. 'I learned to do his dressings and manage his medications. I'm a nurse so some of it comes naturally to me, but it's still a struggle. Eventually we were able to take him home,' she says.

EB affects everything in their day-to-day life. Even changing his dressings can take up to three hours. Eating is difficult and constant blistering means James' eyes are always sore. As soon as he's passed one hurdle, Beata knows there'll be another one waiting for him.

'More healthcare professionals need to know about EB so they can help people like James. Mostly I think I'm coping ok, but some days you just want to cry your eyes out. I just hope he grows up strong enough to cope with whatever the future has in store for him.' Beata's determined to make sure James has the best possible quality of life.



Our Vision

A WORLD WHERE **NO ONE SUFFERS** FROM THE PAINFUL SKIN CONDITION EPIDERMOLYSIS BULLOSA

Our Mission

PROVIDE LIFELONG CARE AND SUPPORT TO EVERYONE IN THE UK AFFECTED BY EB

Our Aims

FUND **PIONEERING RESEARCH** FOR SYMPTOM ALLEVIATION AND, ULTIMATELY, A CURE

PROVIDE **CARE AND SUPPORT** TO THE ENTIRE EB COMMUNITY



Oliver's Story

DEBRA makes a difference...

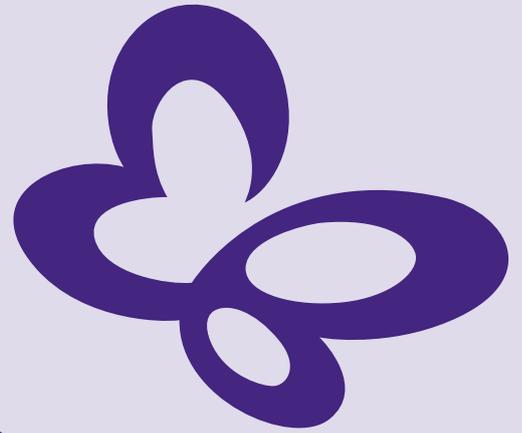
Watching football is the one big distraction that helps 28-year-old Oliver get through each day. He attends matches for his local football team, he's a dedicated Manchester United supporter and he's travelled to Spain to watch Barcelona FC play.

Every time Oliver goes out in public people stare at him. Strangers ask if he's been burned and children ask their parents, 'What's wrong with that boy?' 'It would be so wonderful if people knew about Oliver's skin condition,' says his mum, Sarah. 'He just wants people to recognise what he's dealing with.' Oliver suffers from EB, which has affected more than just his outer layer of skin.

The constant blistering has taken its toll. Continual scarring has bent his back, fused his fingers together and caused his limbs to contract. He is losing his eyesight and damage in his throat means he is always at risk of choking.

Oliver is becoming increasingly isolated. 'EB is so cruel. We've watched him decline - when he was a child he could still walk, but he can't any more. It's so tough watching EB make every day harder for him', says Sarah.

Support from DEBRA has made a massive difference to his quality of life. DEBRA has made it possible for EB nurses to visit Oliver at home and make sure he gets the care he needs with as much comfort as possible. And he's been able to meet up with other people suffering from EB and enjoy a weekend away from home.



STRATEGIC REPORT

Highlights and breakdown of DEBRA's services and income generation activities in 2017 and an overview of future plans.

A MESSAGE FROM OUR CHAIRMAN & CEO

Charitable organisations in the UK have never experienced a more challenging environment than they do now. In the face of this, DEBRA is proud to have helped more people within the EB Community in 2017 than the previous year, including those directly affected by, and working with, the condition.

Support from our generous donors has helped fund pioneering research to enhance the quality of life for EB sufferers, as well as providing additional resources in healthcare with the opening of the Rare Diseases Centre at St. Thomas' Hospital in London. In addition, we supported more families facing EB with important benefits such as financial grants and respite care than in 2016, and we were able to purchase a new DEBRA holiday home in the Lake District.

The EB Community is at the core of DEBRA's charitable activities, and seeking breakthroughs in research and improvements in care is at the heart of what we do. We celebrate our 40th year in 2018 and it serves as a good time to reflect on what we have achieved so far and focus on the way ahead. This is in the context that we are an active member of an international group of DEBRAs.

DEBRA is proud to be funding revolutionary clinical trials, including a study focused on gene discovery and diagnosis, as well as a 'first in EB' trial of a drug aimed at delaying the spread of skin cancer (specifically, Squamous Cell Carcinoma) for those suffering from Dystrophic EB. We are also committing funding to trials focused on reducing the impact of itch and pain, which could lead to a dramatic increase in the quality of life for EB sufferers.

We continue working with the NHS to improve the level of care provided at the four EB centres of excellence and specialist outreach clinics, particularly with podiatry clinics, specialist EB nurses, occupational therapies and dietician services; our EB Community Support Team also works in partnership with clinical reviews.

Each year brings new challenges and opportunities. There is a heightened awareness of the need to safeguard the wellbeing of vulnerable adults and children. We are reviewing and, where appropriate, strengthening our robust procedures to ensure all our members, staff and volunteers are safe and protected at all times. We are also fully prepared for the arrival of GDPR (General Data Protection Regulation) in May 2018, which represents an opportunity to provide a better service and communicate more effectively with the EB Community, our supporters, donors and members of the public.

Financial support for DEBRA grew significantly over the last year, and because of the remarkable efforts of our donors, our customers in the shops and our staff we can continue to make a real difference to people suffering from EB and accomplish even more in the year to come.

David Spence
Chair of Trustees

Ben Merrett
Chief Executive Officer

OVERVIEW

DEBRA is the national charity (incorporated in the UK) supporting those directly affected by, and working with, EB – a potentially fatal skin condition that causes constant pain due to unstoppable internal and external blistering.

DEBRA is registered with the Charity Commission for England and Wales, as well as the Office of the Scottish Charity Regulator (OSCR), the latter required due to DEBRA's Scottish activities that continue to form an important part of DEBRA's UK strategy.

Receiving no direct government funding, the charity relies solely on the generosity of the public to carry out its vital work. DEBRA does take full advantage of generic government incentives (e.g. Gift Aid), which have become very important.

Envisioning a world where no one suffers from EB, the charity continues to provide specialist care to those who need it, support to people and families affected by the condition and hope for the future through funding research that could one day lead to a cure(s).

OBJECTIVES

- Enhance the quality of life for people affected by EB
- Provide continuing services and support to the EB Community
- Develop effective treatments through funding research into EB conditions
- Advocate for the well-being of those affected by EB, and facilitate their full integration into society
- Promote best current practice in treatments for EB
- Increase professional and public knowledge of EB
- Encourage the development of global EB support groups and foster coordination
- Raise sufficient funds to achieve these objectives

In fulfilling these objectives, DEBRA encourages members of the EB Community to get involved with the charity and raise public awareness of the condition.

PUBLIC BENEFIT

DEBRA meets the definition of a public benefit entity under FRS102, s17 of the Charities Act 2011 and Charity Commission and OSCR guidelines. DEBRA provides support to people across the UK living with any type of EB, as well as family members and carers of someone who has EB and those working within the EB Community in a professional capacity.

All people affected by the condition are encouraged to engage with DEBRA to further develop the services and support available. Satisfaction and service development surveys and group discussions with DEBRA's stakeholders continued during 2017, and a patient panel to review research projects was established.

DEBRA's Charitable Activities Committee, led by a trustee living with EB, makes strategic and fundamental decisions on the charitable activities undertaken by DEBRA for the benefit of present and future people with any type of EB.

RESEARCH

DEBRA remains steadfast with its effort to fund pioneering research in the hope of one day finding a cure(s) for EB. Having invested £7.5m on research over the last decade, DEBRA was able to fund 10 on-going or new research projects in 2017 alone, fostering innovation and growth in EB research.

RESEARCH STRATEGY

The breadth of research remains important and is vital to DEBRA's overarching research strategy. DEBRA continues to support research into clinical and scientific endpoints that will support the regulatory pathways for treatments in the future, and the current portfolio of research projects includes pre-clinical exploratory work, early phase clinical studies in small numbers of patients, as well as projects investigating symptom relief. Grant management is at the core of the process, ensuring a complete peer review and reporting structure.

KEY AREAS

Gene Technology

Engaging with the EB Community is important to understanding the overall needs of those suffering from EB. A clearer focus on EB Simplex has been identified; the work at Dundee University, initially looking at gene technology for treating EBS, has wider implications for research into cure(s) of more than one type of EB.

Targeted Cancer Therapy

Following the 2015 grant round, DEBRA funding has now begun for a team of international researchers (including Doctor Andrew South, Professor Johann Bauer and Professor Jemima Mellerio) to investigate 'targeted' cancer therapy, specifically Squamous Cell Carcinoma (SCC). Working closely with Onconova Therapeutics on their development of the drug Rigosertib, patients will be recruited for treatment at two European sites.

Stem Cell

One of the most common symptoms across all patients with EB is debilitating itch. Understanding of itch is minimal and current treatments are not particularly effective. DEBRA committed to continue work with London-based Professors John McGrath and Jemima Mellerio to investigate the specific role stem cell therapy has on itch.

A GATHERING OF LEADING EXPERTS

A summit of the world's top experts in EB, along with recognised experts from wound healing in other disciplines, was held in London in December 2016. The proceedings were published and a wound healing grant round was held in 2017. As a result, twenty-four project applications were initially reviewed and three recommended for funding.

SIGNIFICANT PARTNERSHIPS

DEBRA appreciates the partnerships developed with other research organisations and respects the mutual aims of providing help to the EB Community. Communication, coordination and collaboration with organisations (including other DEBRAs and EB organisations) is paramount to the success of continued international research projects, both in direction and funding. In this spirit, DEBRA continued to administer one project for Cure EB (formerly 'Sohana Research Fund').

RESEARCH BY NUMBERS

£1,275k committed to new research projects

c200 members involved in an online patient research panel

£286k on additional research expenditure

£7.5m spent on research grants over the last 10 years

10 current EB research projects funded by the UK

15 patients taking part in EB clinical trials funded by DEBRA in the UK, with planned recruitment for 15 more

LOOKING TO THE FUTURE

Due to the nature of the condition, there is still a long way to go to find a cure(s) for EB and its subtypes. Because of this, DEBRA will use expert meetings to identify new research opportunities and draw in relevant expertise outside the field of EB; continue funding projects which add to knowledge on the natural history or treatment of EB; as well as building on results obtained from on-going projects and translating clinical findings into meaningful treatments.

AIMS FOR 2018

- Fund up to £1m for research projects in 2018
- Focus on the translation of pre-clinical research into patient studies identifying suitable treatments for cure(s) and control of EB, as well as symptom relief and clinical care programmes that will impact positively on quality of life
- Identify core areas for research and drawing experts from other fields into the EB research community
- Take part in the focused meeting on chronic inflammation and fibrosis leading to the development of cancer in EB (scheduled for May 2018) and participate in the grant round based on the set priorities
- Champion communication, coordination, and collaboration to ensure a coherent approach to EB research, within the UK and worldwide

HEALTHCARE

DEBRA provides funding to deliver a UK-wide specialist healthcare service for people living with any type of EB. This service is provided in partnership with NHS England's Specialised Services Commissioning Team and NHS Scotland who fund the core (NHS duty of care) clinical service.

DEBRA's support enhances the core service through funding increased hours for specialist nurses, dieticians, a podiatrist, as well as supporting initiatives such as the multi-disciplinary outreach clinics.

EB CENTRES OF EXCELLENCE

There are four designated EB Centres of Excellence in the UK based at hospitals in both Birmingham and London: Birmingham Women's and Children's Hospital, Solihull Hospital, Great Ormond Street Children's Hospital and Guy's and St. Thomas' Hospital.

Multi-disciplinary teams consisting of DEBRA Community Support Managers, EB nurses and other specialist healthcare professionals meet at these centres to provide high levels of expertise required to care for people living with EB.

KEY AREAS

Podiatry

Even in its more mild form, EB affects the hands and feet of most sufferers, yet there is very little awareness amongst the podiatry community about the condition. In order to strengthen this service, DEBRA committed £105k over the next three years to fund the development of an accredited EB podiatry training course, as well as a full training programme across the UK, enabling EB patients to receive more expert care.

Clinical Teams

With limited numbers of specially trained EB nurses, DEBRA backed some of the clinical teams business plan applications, which resulted in increased nursing hours to help develop expertise and specialist EB services (e.g. podiatry, dermatology consultant time for clinics and inpatients).

In addition, the NHS also committed to fully fund the podiatry service at St. Thomas' hospital, which had been established and funded by DEBRA for 10 years.

Nursing

Recognising the need to provide further support to existing nursing teams at the two paediatric designated centres of excellence, DEBRA agreed to fund an additional two-year fixed-term nursing post at each location – ensuring the new teams (following multiple retirements and vacancies) become well established and have the time to undertake the required clinical specialist training.

Rare Diseases Centre

DEBRA contributed £250k to the development of the Rare Diseases Centre (RDC) at St. Thomas' Hospital in London, the second largest amount to the project. The RDC greatly enhanced the clinical facilities available to the EB Community and further enables the development of multi-disciplinary working.

SIGNIFICANT PARTNERSHIPS

Collaboration with leading healthcare organisations is vital in providing appropriate care and support to the EB Community. The NHS and DEBRA partnership had a direct impact on increased quality of life for EB sufferers through greater access to specialist care (e.g. home visits, outreach clinics and bereavement support).

In addition, DEBRA funded small pieces of equipment, inpatient grants and inpatient TV viewing, as well as some travel and accommodation to enable individuals and carers to attend appointments and hospital stays. A contribution to further develop the national clinical database was also made.

HEALTHCARE BY NUMBERS

2,000 patients supported by
EB specialists

£715k spent on Healthcare activities

100 days of specialist dietician services

18 specialist EB podiatry clinics

16 clinical supervision workshops

26 specialist EB training grants

Up to 25% of specialist EB nurses costs
covered by DEBRA

LOOKING TO THE FUTURE

The EB Community is at the core of DEBRA's work, so future plans include identifying clinical need and research that aims to improve the quality of life for people living with EB today.

On-going partnership work with the designated EB Centres of Excellence and specialist clinical teams and commissioners will continue to be developed to ensure the provision of care required is met.

AIMS FOR 2018

- Continue funding up to 25% of each specialist EB nurse in the UK
- Support enhanced occupational therapy and dietician services and the development of their clinical best practice guidelines
- Encourage innovative projects and service developments that will enhance the lives of people living with EB
- Implement the DEBRA UK clinical research strategy – encouraging and offering financial support in developing best practice research that will enhance the quality of life of someone living with EB
- Identify the areas of clinical priority, and provide funding, for the development of EB clinical best practice guidelines within the identified areas

COMMUNITY SUPPORT

Liaising directly with members of the EB Community is vital to understanding the needs of EB sufferers and those impacted by the condition. DEBRA continued providing membership and specialist community support services to people across the UK.

ENGAGING WITH THE EB COMMUNITY

DEBRA consistently requests and reviews feedback provided from its members through the use of surveys, focus groups and general meetings. Some of the topics include facilities and accommodation at member events, new projects and publications.

There has been a review of existing printed materials and website content has been updated accordingly; however, further development is still required. As such, an editorial group consisting of members and key DEBRA staff has been established to assist in this area.

KEY AREAS

Information and Liaison Support

The quality of life for members of the EB Community continued to be enhanced by DEBRA's support. Identified areas required for assistance with particular issues include: welfare rights and reform, housing, employment and independent living.

DEBRA offers a range of benefits to its members, which is why a continued area of focus remains with contacting people suffering from EB who are not taking advantage of the services. These services are provided based on feedback received from the EB Community and are advantageous to those impacted by the condition.

Support Grants

DEBRA provides support grants to members for emergent needs and to assist in covering costs for basic quality of life improvements such as white goods. Over the year, there was a 24% increase in the number of support grant applications and a 25% increase in funding required when compared with 2016, which is most likely a result of increased awareness of funds available. In addition to DEBRA's support grants, the Community Support Team successfully aided members of the EB Community in accessing financial support from other sources.

Community Events

There are many stories of EB Community members feeling isolated and alone. It is important for DEBRA to provide opportunities across the UK where members can meet, share stories and learn more about how others manage the condition.

DEBRA provides the EB Community with a UK-wide EB get together event known as Members' Day. Due to high demand, the event was held over two days for the third year in a row. This event provides an excellent opportunity for members of the EB Community to meet with other members and professionals, as well as to learn more about research and living with EB.

In addition to the annual event, DEBRA also hosted five regional member events across Scotland, Oxford and Birmingham, as well as a long weekend away. The latter event provided opportunity for respite, peer group support and developing independence and was highly rated by attendees.

Respite Care

Having the opportunity to go on holiday is often out of reach for many people within the EB Community, either due to costs or inadequate facilities. In 2017, DEBRA purchased a new holiday home in the Lake District and now boasts five homes, which were booked to full capacity over the peak seasons.

SIGNIFICANT PARTNERSHIPS

DEBRA works with, and is a member of, other organisations (including Disability Rights UK, Genetic Alliance UK and Carers UK) to enhance the services available to the EB Community.

COMMUNITY SUPPORT BY NUMBERS

505	individuals accessed the DEBRA Community Support service	£772k	spent on Membership and Community Support activities
233	support grants were awarded	2,640	individuals in the free DEBRA membership scheme
111	EB hospital clinics attended	630	holiday days taken in DEBRA's five holiday homes
409	people attended Members' Day	378	home visits took place

LOOKING TO THE FUTURE

To best meet the needs of the EB Community, DEBRA plans to increase engagement with its members to help shape and focus care and support service developments and improved membership benefits, including more regional and local events.

Publications and the use of multimedia will be reviewed and developed to ease the sharing of information; the development of community support profiling to achieve a more proactive service is anticipated.

A new or replacement holiday home is planned in 2019, and funds will be utilised to expand the team in order to deliver support to a growing number of members and undertake new/enhanced initiatives.

AIMS FOR 2018

- Provide a professional Membership and Community Support service to members of the EB Community across the UK
- Expand and develop the Membership and Community Support Teams to meet current needs and increasing demand
- Ensure sufficient funds remain available within the support grant budget allowing for the projected rise in applications for urgent and essential goods and services
- Encourage and support innovative research, projects and service developments that will enhance the lives of those affected by EB
- Increase membership and engagement of members
- Introduce a learning and education support grant fund for members to develop skills and social interaction
- Introduce a number of local and smaller member events across the UK
- Update and enhance the range of publications and improve the accessibility of information available to members and healthcare professionals
- Maintain membership of external organisations (such as Genetic Alliance and Disability Rights UK) facilitating DEBRA's ability to campaign for the EB Community

INTERNATIONAL

International collaboration and coordination is vital in developing effective treatments and a potential cure(s) for EB. DEBRA works closely with other DEBRAs globally and external groups to ensure work is not duplicated and best practice information is shared with all relevant parties – including researchers, clinicians, charities and pharmaceutical and biotechnology organisations.

COLLABORATING AT THE INTERNATIONAL LEVEL

The UK's strategy for international collaboration remains consistent with the following key objectives:

- Improve clinical care through developing clinical networks, sharing knowledge and developing clinical practice guidelines
- Raise awareness of EB and the care required by advocating on behalf of the UK Membership
- Improve joint working on communication, campaigns and projects

KEY AREAS

Coordinating International Research Projects

DEBRA is a founding member of DEBRA International, an umbrella organisation with over 50 members in other countries that aims to ensure all EB research activity is coordinated worldwide.

Enhancing Global EB Care and Best Practice

Alongside other DI members, DEBRA is assisting the development of an International EB Patient Registry and Clinical Best Practice Guidelines.

Raising EB Awareness around the World

Awareness of the condition with the general public is poor and DEBRA aims to raise its profile significantly in the coming years through integrated, coordinated awareness campaigns together with other DEBRA International groups.

SIGNIFICANT PARTNERSHIPS

DEBRA supports a small number of international projects and makes a contribution to the running costs of DEBRA International; however, its volunteers also make a significant contribution. DEBRA's Vice-Chair, Mike Jaega, is President of DEBRA International and leads the development of its important activities. DEBRA ensures good value is received from DEBRA International's activities.

DEBRA International also links closely with the EB Without Borders (EBWB) group in a collaborative effort to assist EB sufferers in need around the world, particularly in those locations where a leading DEBRA organisation is not present.

INTERNATIONAL BY NUMBERS

56 DEBRA groups worldwide

2 international clinical best practice guidelines, funded by the UK, Podiatry, and Hand Surgery and Rehabilitation

30 EB research groups worldwide have received DEBRA funding over the last 5 years

189 individuals taking part in the DEBRA International Research Involvement Network (RIN)

LOOKING TO THE FUTURE

Working with the aims of the DEBRA International group, DEBRA plans to bolster their activities through further funding of services (particularly in the development of international clinical best practice guidelines and EB patient registry) and assistance from personnel where required.

AIMS FOR 2018

- Provide funding for the development of international clinical best practice guidelines
- Coordinate international research grant rounds
- Work with other research groups to ensure information sharing and to prevent duplication
- Begin planning for the 2020 EB Conferences taking place in London



PUBLIC ENGAGEMENT

RAISING AWARENESS

A focus for DEBRA in 2017 was to continue to raise awareness of EB. Too many people do not know about the condition, do not understand how it affects people and do not understand what a difference is made by the charity dedicated to supporting those living with EB.

THE EB COMMUNITY

The EB Community itself is a disparate one: there are many different types of EB and it manifests itself in different ways to such a degree that no two people suffer in the same way, even if they have the same type; it is treated in different hospitals by staff trained to support children in one location and adults in another; the research teams differ in location and intent and their funders come from many different places; the pharmaceutical companies working to improve the lives of those living with EB all have different aims and objectives; and yet, the one charity trying to work with the whole EB Community is DEBRA.

KEY AREAS

Connecting DEBRA with the EB Community

Steering away from the traditional appeals and campaign route, the #FightEB campaign was designed to reflect and engage with the whole EB Community. The aim remaining simple – to raise awareness of EB and to give people a mechanism to get involved with supporting DEBRA.

The campaign launched in October 2017 and was fronted by DEBRA Member James Dunn, an inspirational young man whose EB did not affect his outlook on life. As a speaker at the Members' Day event in May 2017, James told everyone present to 'keep smiling no matter what life throws at you' – and he was good to his word until his unfortunate passing.

A few months later other individuals and families wanting to tell their own stories about living with EB were added to the campaign. At the start of 2018 the website (www.fighteb.org.uk) told 8 different stories reflecting the breadth of the condition and how it affects people in so many different ways.

The #FightEB campaign closed on 28 February 2018 to coincide with Rare Disease Day; however, the #FightEB mantra is now linked with the DEBRA brand as the fight to end EB continues.

Engaging with the Public

In efforts to increase awareness and engage more with the public, a decision was made to further develop DEBRA's digital presence, which included routine posting, responding to and sharing information on Facebook, Twitter and Instagram, the latter platform being launched in April 2017.

Digital public engagement was measured throughout 2017. There were a total of 254,346 people who visited DEBRA's website – compared to 199,387 in 2016. Social media also saw an increase:

- Facebook – 15% more likes on the page (2016:7,000; 2017:8,012)
- Twitter – 20% increase in the number of followers (2016:3,500; 2017:4,200)
- Instagram – over 450 followers on this new platform

Team Restructure

After analysing information from other charities, a decision was made to restructure the marketing department to reflect the differing needs of the charity. Greater investment has been placed in DEBRA's digital capability.

SIGNIFICANT PARTNERSHIPS

The #FightEB campaign was heavily promoted using social media, as well as in the traditional press, having reached a pinnacle with the involvement of Spider-Man actor, Tom Holland. Tom's own fundraising realised £42k and caused a huge spike in online activity. The appearance of James Dunn alongside Tom Holland on the Good Morning Britain sofa further enhanced this engagement.

PUBLIC ENGAGEMENT BY NUMBERS

239k emails were sent to DEBRA members and supporters

19.1k copies printed of DEBRA's member and supporter magazines

254,346 people visited the main DEBRA website

8,000+ likes on Facebook

4,200 followers on Twitter

450 followers on Instagram, which was launched in the year

30 information leaflets covering a range of services accessible to DEBRA members, all available for download from the DEBRA website

LOOKING TO THE FUTURE

DEBRA plans to continue the #FightEB movement, as it is now so intrinsically linked with the DEBRA brand. In particular, the hashtag of #FightEB will continue to be pushed alongside many social media posts, as well as #EBawareness and other common charity tags (e.g. #fundraisinghero).

AIMS FOR 2018

- Develop appeals for 3-5 core projects across DEBRA's breadth of work
- Grow social media platforms and increase visual assets
- Produce regular editions of the members' magazine, InTouch, and the DEBRA News supporter magazine
- Send regular e-news updates to all members, supporters and other interested parties
- Create a range of collateral showcasing DEBRA's work
- Proactively place EB stories within the local and national media
- Build on and continue the success of the #FightEB campaign
- Strengthen resources across digital, PR and marketing

PUBLIC ENGAGEMENT

RAISING AWARENESS

THE #FIGHTEB STORY

DEBRA recognises the prevalence of technology in our daily lives with social media being one of the leading drivers. It is important to ensure DEBRA's brand is represented within this media in an engaging way.

The #FightEB movement aims to:

- Increase DEBRA's presence across social media and the digital environment
- Spread EB awareness to those who may not have heard of it or know anything about the condition
- Become more engaged with the EB Community
- Better reflect all types of EB sufferers

After giving a compelling and motivational speech at the 2017 DEBRA Members' Weekend event, James Dunn agreed to become the frontman for the #FightEB campaign. James' drive and determination to not let EB beat his spirit is one that resonates with other members of the EB Community and what forged the original concept - together, we #FightEB.

TIMELINE OF EVENTS

JUNE James was not shy in front of a camera or behind. He was an aspiring photographer living with a severe form of EB. Having previously featured on the BBC's Big Life Fix, James was happy to lend his support to raise EB awareness and front the #FightEB campaign.

OCTOBER DEBRA initiated its first-ever integrated awareness campaign and fundraising appeal. Through digital and traditional methods, the campaign succeeded in reaching its fundraising target and raising awareness with more people than ever now knowing of the condition.

DECEMBER After meeting James earlier in the year on a photo shoot, celebrity Tom Holland decided to get involved with the #FightEB campaign. The Spider-Man actor auctioned a limited edition print, taken by James.

PROMOTING THE CAMPAIGN

The campaign has been widely promoted, particularly within DEBRA's retail shops through displaying posters and across social media, which directed viewers to the dedicated www.FightEB.org.uk website.





James' Story

Leaving a legacy...

Meet 24-year-old James Dunn. James was diagnosed with an aggressive and, ultimately, fatal form of cancer caused by his EB. He suffered from EB, but was determined to live life to the full.

Before his passing, James was on a mission to leave a legacy: 'If I can say that I helped to make EB a well-known condition that everyone understands, that will be a great legacy to leave behind.'

The more well-known EB is, the faster EB awareness will spread.

James helped launch DEBRA's #FightEB campaign, which went on to raise the profile of EB across the UK and abroad.

James once said, 'I don't know how long I have left, but I know I'm too young to pass away from this condition. I want to fight EB. I want to beat EB.'

Living by the philosophy to 'just keep smiling' no matter what, James kept smiling throughout his fight with EB.

Sadly, James' fight ended on 7 April 2018.

FUNDRAISING

SUPPORTING THE EB COMMUNITY

As a charity, DEBRA is reliant upon its fundraising activities to deliver its charitable objectives. Everything people do to help support DEBRA – from hosting a fundraising event to donating directly – impacts the EB Community.

FUNDRAISING MISSION

The Fundraising Team strives to raise as much money as possible to help support the work of the charity. DEBRA is committed to making a difference today (Healthcare and EB Community Support services), as well as working towards a better future (funding pioneering research projects).

DEBRA's fundraising efforts include hosting a portfolio of high quality major events, as well as traditional fundraising methods of supporting individual fundraisers, applying to major trusts and grants and partnering with businesses for charity of the year status.

KEY AREAS

Major Events

DEBRA has a wide and varied portfolio of major events including the prestigious DEBRA Golf and Shooting Societies. Particular successes in 2017 were The Great Chefs Dinner, The Butterfly Ball, The Wine Challenge, Fight Night and a number of very popular golf days.

These events would not be successful without a number of key ingredients: the individuals who enable us to reduce costs by considerable margins; the sponsors who further reduce costs and provide auction and raffle items; the incredibly hard working team of volunteers who make up the Events Committee and the people who patronise DEBRA's events.

In 2017 the DEBRA Events Team raised £299k in total. The challenge moving forward is to find new markets to sell into whilst maintaining the high quality that people expect of us.

Individual Fundraisers

DEBRA is hugely grateful to the hundreds of people who have undertaken their own personal challenge for the charity. In 2017, individual fundraisers helped raise £317k.

A special thanks to those from within the EB Community who have fundraised for DEBRA – either by allowing the charity to tell their story as part of the #FightEB Campaign or who have sought and asked for support within their local community.

A particular mention to the Pearson family from North Norfolk; the family has now raised an impressive £50k over the past decade through local community fundraising.

The charity is indebted to everyone who chooses to support DEBRA more privately as individual supporters or as regular givers.

Sports and Challenges

Many charities purchase places for some of the more sought after sports events, whether the challenge is a run, walk, cycle, swim or trek. DEBRA actively participates in some of these events and managed to raise £80k from these events in 2017.

Legacies

Despite a lack of proactive marketing within this area, £282k legacy income was received or accrued in 2017.

SIGNIFICANT PARTNERSHIPS

In September 2017 DEBRA was a recipient of the annual BGC Charity Day and delighted with the individual support from its Royal Patron, HRH Countess of Wessex. She was joined by a host of celebrities lending their support to DEBRA and a number of other charities. The opportunity allowed James Dunn to attend and photograph many of the celebrities.

DEBRA is appreciative to the grant making trusts that support the charity to make such a difference to the EB Community. Special mention to The Brother's Trust, the Enid Linder Foundation and the Burdett Fund for Nursing.

The Rare Diseases Centre at St. Thomas' Hospital opened its doors to patients in November 2017. DEBRA could not have delivered on its financial commitments to the project without the support of the following trusts: Sir Jules Thorn; Garfield Weston Foundation; GF Eyre Trust; and the Kirby Laing Foundation.

FUNDRAISING BY NUMBERS

£299k net income from the DEBRA Major Events

£104k net income from the DEBRA Golf Society

£317k net income from individual donors

£80k net income from the major challenge events

£530k net income from the legacy and trust donations

LOOKING TO THE FUTURE

DEBRA celebrates its 40th anniversary in 2018 and hopes to capitalise on this milestone at its prestigious events, including a full programme of exclusive dinners featuring some of the very best chefs, clay pigeon shoots at exclusive locations, golf days at some of the finest courses, sporting lunches and the annual Fight Night.

A special event is also planned to say thank you and recognise those who have helped DEBRA grow to where it is today and identify those who want to help the charity with the next step of its journey.

AIMS FOR 2018

- Deliver the fantastic programme of events that is lined up for the year ahead to the highest expectation and greatest return to the charity
- Utilise the events programme to progress relationships with major supporters, current corporate supporters and sponsors
- Identify new corporates and major supporters
- Empower people raising money for DEBRA, particularly those with a close connection to EB, to raise significant sums from their own local communities
- Raise awareness of the importance of legacies and the difference they make to enable DEBRA to support the EB community
- Strengthen engagement with the EB community

RETAIL

DEBRA ON THE HIGH STREET

Retail has been a driving force for generating income for many years. In 2017, DEBRA's Retail chain of both traditional and furniture and electrical (F&E) shops produced its best ever net income. Like-for-like (LFL) growth, particularly in F&E, has been well above the sector average. The charity also benefits from public awareness from all of its high street locations.

RETAIL STRATEGY

The Retail strategy remained agile, and the introduction of discount stores and extended trading hours continued in 2017 whilst additional initiatives were considered to create more donations for the traditional shops. Enhanced management information assisted in price optimisation and in gaining a better understanding of the shop-by-shop variance in demand for donated items. This enabled an informed response to customer demand.

KEY AREAS

Shop Openings and Closures

Some of the recent shop openings have not performed as well as expected, and the plan is to consolidate the chain as well as being open to good expansion opportunities. The Scottish shops have particularly struggled and a re-organisation has taken place to respond to this.

Furniture and Electrical

F&E shops are now proving themselves with improvements in profitability following the rapid expansion in 2016. However, not all sites attain the levels that are expected but some exceed expectations. The initial investment in this strategic development has been fully repaid and these shops generated more than £400k in 2017.

Retail Gift Aid Scheme

The Retail Gift Aid Scheme was buoyant in the year; shop staff endeavour to, wherever possible, obtain a valid Gift Aid declaration when donations are made. Together with retail donations this represented total net income at £1,258k (2016: £1,187k), which is 80% of total retail net income.

SIGNIFICANT PARTNERSHIPS

DEBRA recognises that its retail chain wouldn't be successful without the help of those who manage, work and volunteer in and maintain the shops – a dedicated group of more than 1,250 individuals.

At the end of 2017, DEBRA's shop portfolio spanned 131 locations: 120 traditional (nine openings and four re-locations in the year) and 11 F&E. The current portfolio is made up of four freeholds, 108 leaseholds and 19 temporary shops.

RETAIL BY NUMBERS

12% margin achieved

£1,192k received through the Retail Gift Aid Scheme

9 traditional shops were opened, plus 4 relocations

300k+ volunteer hours contributed

6.2% growth in like-for-like sales

131 shops at year end, 120 traditional and 11 F&E

4 Freeholds, 108 leaseholds and 19 temporary shops

LOOKING TO THE FUTURE

DEBRA's key aim for Retail is to improve on current margins, with a goal of 20%; a target of 18% margin is forecasted by 2020, which is a vast improvement on the 11% margin achieved in 2016.

Engagement and efficiency of existing staff and volunteers will continue to play an important role in 2017. Structured training and induction programmes will be delivered, and communication to all staff and volunteers will be improved by having annual appraisals, six managers' meetings and regular one-to-one meetings.

Continued growth in DEBRA's Retail division brings greater recognition of the charity's work and provides opportunities for friends of DEBRA to help in a practical way (i.e. donating goods, working at one of the shops or volunteering time).

AIMS FOR 2018

- Consolidate the estate if a reasonable return can't be made from challenged shops
- Improve margins with a range of innovations
- Grow like-for-like sales income by 3% – improved data analysis will help drive this
- Increase the number of donations to traditional shops
- Encourage members of the EB Community to volunteer in their local shop



OUR PEOPLE

From its origins, 40 years ago, of being a small support group for parents affected by EB, DEBRA has grown significantly in income and personnel, and at the end of 2017, DEBRA employed just over 380 paid members of staff. The range of jobs is broad, from managing a charity shop and organising fundraising events to processing income and supporting members with home visits, but each contributes significantly to the service that DEBRA can provide to its membership.

EMPLOYEES

Learning and Development

Attracting, developing and retaining the right people is crucial for DEBRA's success. All members of staff are encouraged to continually develop their skills, and 2017 saw the introduction of e-learning, making learning readily accessible for all and delivered in such a way that is affordable for the organisation.

Team Events

In April of each year DEBRA brings together many of its staff and Trustees from across the UK, to the All Staff Conference, to share knowledge, promote internal communication, provide opportunities to recognise and reward achievement and inspire continued engagement. The 2017 event was held in Nottingham and spanned over two days, and several members from the EB Community also attended to give an insight into how the condition affects their day-to-day life.

The year ended with a team day for the administrative and management employees, which provided an opportunity for staff to share the progress in their work with colleagues. The 2017 event was held in a cinema to showcase the increasing amount of video material available communicating the various aspects of living with EB; an awards dinner followed to celebrate individual and team achievements.

Apprenticeships

From April 2017, DEBRA started making payments in respect of the apprenticeship levy. Based on a contribution of 0.5% of the annual wage bill (with a standard allowance of £15k), funds are accumulating in a specific levy account, from which payment has been made towards training for existing members of staff or for the training of new employees who are recruited as apprentices.

In the last quarter of 2017, apprenticeships in Customer Services, Business Administration & Management and Team Leading were offered to existing staff in two Retail areas. The apprenticeship programme will be expanded in 2018.

PAY POLICY

Rates of pay and salaries within DEBRA are set at a level that are fair and legally compliant, proportionate to the requirements of each role, sufficiently competitive within the charity sector to attract and retain the best employees for each position, rewarding high performance, respecting equality in the workplace, and recognising the charitable status of the organisation.

In accordance with the Equality Act 2010 (Gender Pay Gap Information) Regulations 2017, DEBRA has reported pay data for the 'snapshot' date of 5th April 2017. The full Gender Pay Gap Report 2017 is available on DEBRA's website, but the key metrics that have been reported are on the opposite page.

Table 1: Summary Gender Pay Gap Report

Description	Gender Pay Gap
Difference in hourly rate of pay – mean	11.4%
Difference in hourly rate of pay – median	0.6%
Difference in bonus pay - mean	5.5%
Difference in bonus pay - median	- 35.0%
Percentage of employees who received bonus pay - male	33.3%
Percentage of employees who received bonus pay - female	40.4%

Band	Description	Males	Females
A	Includes all employees whose standard hourly rate places them at or below the lower quartile.	25.5%	74.5%
B	Includes all employees whose standard hourly rate places them above the lower quartile but at or below the median.	25.3%	74.7%
C	Includes all employees whose standard hourly rate places them above the median but at or below the upper quartile.	22.1%	77.9%
D	Includes all employees whose standard hourly rate places them above the upper quartile.	28.4%	71.6%

DEBRA's mean gender pay gap is 11.4%, which tells us that, on average, the hourly rate of pay that female employees receive is 11.4% lower than the rate male employees receive, which equates to £1.28 ph in monetary terms.

This is significantly below the figure recorded for organisations within the UK with a similar financial turnover and a similar number of employees. The national average is 18.4%, and within the arena of 'human health and social work' organisations, the average is 25.0%, which is more than double DEBRA's percentage.

It is however slightly above the charity sector average of 9.8%, but this is not surprising, as DEBRA is unusual in the sector for having a disproportionately high number of retail outlets for a charity of its size; consequently, a large proportion of the workforce is made up of retail staff, who are predominantly female, and generally paid at lower levels than the administrative and management roles which are more equally represented by men and women.

Although the mean gender pay gap for 2017 is comparatively good, reflecting existing policies for both Pay and Equality, the aim is to reduce the gap further during the next twelve months. Within Retail, an exercise to evaluate jobs will be carried out to ensure that there is no unconscious bias to pay a higher hourly rate of pay for a few jobs, which are essentially at comparable levels, but which tend to attract men rather than women.

OUR PEOPLE

PAY POLICY (CONTINUED)

All aspects of pay – including hourly rates, salary levels, reviews, incentive schemes and termination costs – are considered by the Quarterly Pay Review Committee, which reports to the Board of Trustees. During 2017, the organisation developed its Pay Policy, to ensure that Trustees are actively involved in the process of determining rates of pay/salaries, as well as individual rewards in respect of high performance. The Chair, Vice Chair and Treasurer decide the remuneration of the CEO.

In December 2017, the annual pay review awarded a pay increase of 2% for all staff.

In accordance with the Charity Statement of Recommended Practice, DEBRA discloses:

- All payments to Trustees (no Trustees are paid) and reimbursed expenses;
- The number of staff in receipt of £60k pa and above (in bands of £10k);
- Employer pension contribution.

EQUAL OPPORTUNITIES

DEBRA is committed to developing a positive working environment that is not only free from discrimination, victimisation and harassment but is also one where people treat each other with mutual respect regardless of age, disability, gender, marital or civil partnership status, pregnancy and maternity, gender reassignment, race, religion and belief, sexual orientation, irrelevant offending background, responsibility for dependants, economic status or political values.

The benefits that derive from having a diverse workforce are highly valued. In particular, the involvement of people affected by EB is actively sought in all aspects of the charity's work.

SAFEGUARDING AND REPORTING OF CONCERNS

Safeguarding

The charity recognises that the protection of children, young people and vulnerable adults who have any contact with DEBRA is essential, and has accordingly developed a comprehensive safeguarding policy.

Within the Community Support Team there is regular contact with EB families, and these members of staff are appropriately trained to an advanced level and required to subscribe to the DBS (Disclosure & Barring Service) 'update' service.

In addition, DEBRA recognises that amongst the paid staff and volunteers, there will be adults and young people who may be regarded as 'vulnerable', and therefore all members of staff are required to comply with the 'Safeguarding Vulnerable Adults and Children Policy' and undertake basic training in safeguarding, to be able to recognise potential abuse and know how to report it.

Any reported allegation of abuse will be investigated thoroughly and appropriately reported by the team of trained 'Designated Safeguarding Officers'.

Grievances

The aim of the grievance procedure is to allow employees an immediate means by which a genuine grievance relating to their work can be aired and resolved. Use of this procedure should avoid the unnecessary build-up of stress, tension and aggravation by an employee nursing a grievance.

Bullying and Harassment

The charity has zero tolerance of bullying or harassment in the workplace, and takes steps to ensure that the working environment is free from this unacceptable behaviour by informing employees of the procedures to follow should they encounter such issues.

Whistleblowing

Where there is legitimate evidence of fraud or malpractice by workers or officers of the charity, which is reported in accordance with the Whistleblowing procedure and constitutes a 'qualifying disclosure', the matter will be fully investigated and appropriate action taken.

VOLUNTEERS

The contribution of volunteers continues to be a significant and essential resource to DEBRA. Within Retail over 1,000 individuals commit to regularly volunteering, contributing in excess of 300,000 hours over the year (the equivalent of approximately 170 full-time employees).

During 2017, improvements in the administration of volunteering were implemented to ensure that accurate data could be recorded without requiring additional HR resources. However, towards the end of the year, the decision was made to appoint a dedicated Volunteer Manager in 2018 to further develop the volunteer resource to benefit all areas of the charity, but with particular focus on supporting the EB Community Support and Retail functions.





Gabrielius' Story

Playing like other kids...

Gabrielius is just like other kids. He's energetic and smiley and he loves to play football. But his skin is as delicate as a butterfly's wing - any form of physical contact could permanently damage his skin. For this five-year old, playtime is simply another painful challenge. He just wants to be able to play like other kids. Gabrielius suffers from EB.

His parents struggle to watch him in agony every day. 'If Gabrielius gets a blister, he'll try and ignore it. But we have to step in and lance it, otherwise it'll get worse and the damage done will never heal properly. He knows to tell his friends to be careful around him, but that's not the same as being able to play like other kids,' says his dad, Linas.

Gabrielius' parents want him, and other people like him, to be able to live life free of EB. EB dominates every aspect of life for the whole family. Gabrielius' mum, Joileita, gave up her career to care for him full time. Linas had to quit his job to find one that didn't demand overtime. But in spite of all their efforts, Gabrielius never experiences a day without pain, and DEBRA has been able to provide support to their family when needed.

FINANCIAL REVIEW

OVERVIEW

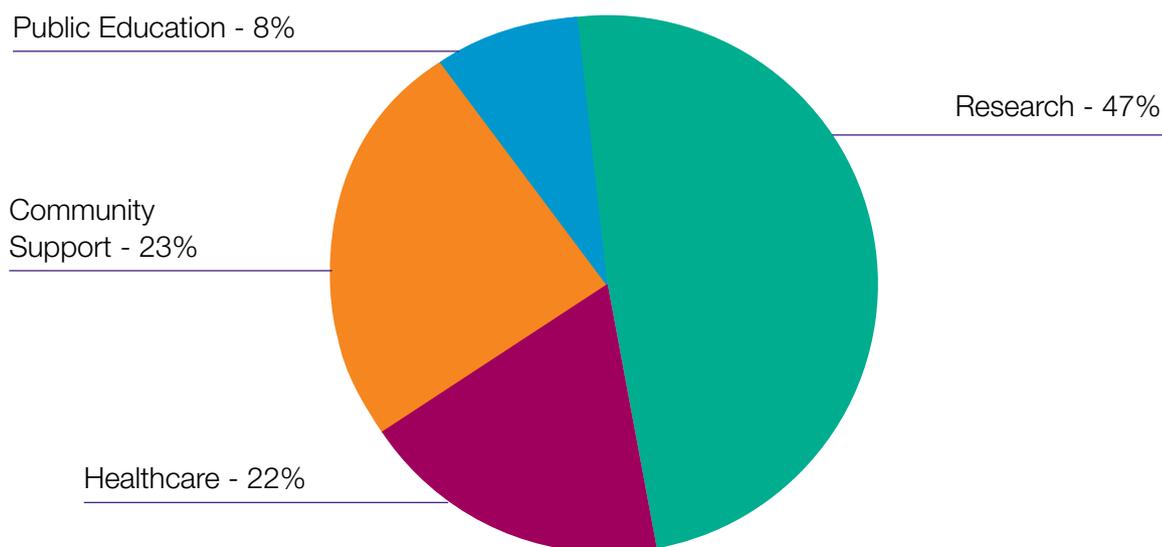
DEBRA's accounts show the financial affairs of the charity for the year ended 31 December 2017. The charity's net income after accounting for the costs of raising funds (principally, charity shop trading costs) was £3,000k. Expenditure on charitable activities was £3,299k, leaving a deficit of £299k for the year.

Gross income during the year was £16,182k, a growth of 14% compared with 2016. There was a significant improvement in fundraising performance, aided by the #FightEB appeal. Retail enjoyed the financial benefits of a shift in the year towards consolidation, rather than expansion in shop numbers. Net income available for charitable spend grew by 28% from £2,343k in 2016 to £3,000k in 2017.

CHARITABLE SPEND

Charitable spend in 2017 was significantly more than 2016, partly from two large projects originally planned for 2016 that slipped into 2017. A contribution of £250k to the St. Thomas' Hospital Rare Diseases Centre was made in February 2017, as well as commitment of £463k to a pioneering cancer trial. The charity continued to invest in Research during 2017, costing £1,561k (2016: £509k), whereas £772k (2016: £691k) was spent on Community Support initiatives, £715k (2016: £267k) on Healthcare services and £252k (2016: £248k) on Public Education.

Chart 1: Charitable Expenditure 2017



There are plans to maintain this increased charitable spend in future periods, demonstrated by the Trustees' decision to designate £1,698k for future research projects, as significant sums will be needed in the near future to continue funding expensive clinical and other trials.

The deficit in the year led to a decrease in net assets from £4,377k to £4,077k. There was £2,049k in the general fund, £1,948k in designated funds and £80k in restricted funds.

FINANCIAL REVIEW

SUMMARY

Table 2 summarises the highlights of DEBRA's financial performance over the last five years. During 2017, non-trading gross income grew by 22% from £2,832k to £3,468k. Net trading income achieved through the shops (including Retail Gift Aid and donations received in the shops) and fundraising events also increased significantly from £1,517k to £1,874k between 2016 and 2017. A prudent accounting policy is followed, whereby the majority of set-up costs incurred for the new shop openings are expensed in the period they are incurred.

The figures are distorted slightly by amortisation of negative goodwill in 2016, 2014 and 2013, averaging £212k in each of those years.

Table 2: Financial Summary

£'000

	2017	2016	2015	2014	2013
Total income	16,182	14,136	12,501	11,881	11,360
Non trading income	3,468	2,832	2,768	2,938	2,968
Net trading income	616	330	34	639	504
Net trading income including retail gift aid and donations in shops	1,874	1,517	1,035	1,541	1,325
Non trading fundraising costs	1,083	819	763	736	564
Charitable expenditure	3,299	1,715	2,524	3,266	2,187
Retained surplus/(deficit)	(299)	628	(486)	(425)	720
Retained surplus/(deficit) as a % of income	(1.8%)	4.4%	(3.9%)	(3.6%)	6.3%
Net current assets	3,951	3,340	2,905	4,034	3,991
Unrestricted reserves	3,997	4,301	3,732	3,650	3,253
Grants payable within 1 year	1,156	1,519	1,694	1,490	1,202

In 2017 for every £1 raised 81p (2016: 54p) was spent on charitable activities. Cost to income ratios for charity shops are high throughout the charity sector, which impacts significantly on fundraising efficiency. In addition, DEBRA has a very high proportion of income generated through its retail activities that compounds the problem in calculating a meaningful ratio. However, if income from trading activities is considered net of running costs instead of using gross trading income, this more realistic ratio is generated. This differs greatly to the fundraising efficiency ratio published on the Charity Commission website, which takes no account of the overhead costs incurred in running, in DEBRA's case, proportionately a very large retail operation.

The charity's fixed assets comprise the premises and equipment required to operate trading activities; premises, furniture and equipment required to operate the charity's offices; and five holiday homes held for the use of those affected by EB. The rest of the charity's assets are held to promote the purposes of the charity through its support services and research programmes.

RESERVES POLICY

DEBRA holds reserves to ensure the charity is able to continue supporting its beneficiaries and as a buffer for short-term cash flow needs.

The Trustees' reserves policy in 2017 was to maintain minimum cash-backed free undesignated reserves at £1,300k, to which the charity adhered. DEBRA has a high proportion of retail income, which provides a stable and reliable income stream. However, this incurs a high cost base, and the minimum reserves figure is calculated as one month's costs (excluding rent) plus six months' rent.

The charity's income is to some extent dependent on a few large fundraising events at specific times in the financial year, as well as seasonal variations in the trading performance of the shops.

Total reserves at the end of 2017 were £4,077k, including £80k in restricted funds. Cash-backed free reserves before designations were £3,248k, of which £1,948k was designated for specific purposes, bringing the total cash-backed free reserves after designations to £1,300k. Cash-backed free reserves are calculated by subtracting fixed assets from unrestricted reserves and adding back 50% of unrestricted freehold and long leasehold property. This is the value that could be mortgaged at short notice, thus representing reserves that can be accessed immediately.

Future Research Fund

A total of £1,698k was available in the designated fund for future research, which is in line with the charitable objectives of DEBRA, and is anticipated to be spent in the next 1-2 years.

Nursing Continuity Fund

The amount of £200k was made available in the designated fund for nursing continuity. This fund was previously for new healthcare and community support projects, but in 2017 the Trustees' re-designated the purpose of this fund to cover the cost of the continued nursing service to the EB Community for six months in the event of the NHS withdrawing current levels of support. It is anticipated this fund will be spent in the next 5-10 years.

EB Conferences Fund

The Trustees established a new designated fund in 2017 for the 2020 EB Conferences to be held in London and hosted by DEBRA. There was a balance of £50k in this fund at the end of 2017. It is anticipated this fund and additional monies will be spent in the next 2-3 years.

General Fund

There was £2,049k in the general fund, of which £1,157k can only be realised by disposing of tangible fixed assets. The Trustees are satisfied that there are sufficient cash balances to meet legal commitments as they fall due.

INVESTMENT POLICY

Trustees are authorised under the Articles of Association to invest any monies not immediately required for its objects in or upon such investments, securities or properties as may be thought fit.

DEBRA aims to apply its income in support of its charitable objectives, and further investment is considered as an interim measure in respect of as yet uncommitted cash surpluses. All investment activities involve risk and reward, and the policy is to achieve a satisfactory return whilst minimising risk.

During 2017, the charity took the view that this was best achieved by investing funds not immediately needed in short-term money market deposits through Lloyds Corporate Markets.

FINANCIAL REVIEW

EXPENSES POLICY

DEBRA has expenses policies for both staff and trustees and also has a PAYE dispensation in place. Expenses that have necessarily been incurred by staff and trustees in performance of their duties are recoverable from DEBRA. Expenses will only be reimbursed if they meet the following criteria:

- No personal benefit could be derived from the expenditure by the employee concerned
- The expenditure is reasonable and represents only additional costs to those that would normally arise on a personal basis
- There is a clear charity justification for the costs
- The expenditure does not represent a form of payment to a third party for work undertaken on DEBRA's behalf

Any expenses that do not meet the criteria above are regarded as a benefit by HMRC and as a matter of policy DEBRA does not reimburse such expenses.

FUNDS

The majority of DEBRA's funds are unrestricted in application and are held in a general and three designated funds. Where funds are received that are restricted in their application to specific purposes or activities, these are held in a restricted fund. Details of restricted funds and designated funds are set out in Note 15 of the financial statements.

ASSET COVER FOR FUNDS

Note 16 sets out an analysis of the assets attributable to the various funds. These assets are sufficient to meet the charity's obligations on a fund-by-fund basis.

RELATED PARTIES

DEBRA has a 100% beneficial interest in DEBRA Trading Ltd, whose principal activity is the sale of promotional items on behalf of the charity. For information, the company's results are shown separately in Note 21 of the financial statements.

INTERNAL FINANCIAL CONTROLS

The Trustees have conducted a review of the effectiveness of the charity's internal financial controls in 2017, using the Charity Commission financial controls checklist. This review concludes that the controls are relevant, appropriate to DEBRA and are not too onerous or disproportionate.

PRINCIPAL RISKS AND UNCERTAINTIES

The Trustees have established a register for all identified major strategic, business and operational risks identified by them to which the charity is exposed and confirm that these have been reviewed regularly during the year by the Finance, Risk and Audit Committee (as well as annually by the Trustee Board) and that systems and procedures have been established to manage these risks. The initial responsibility for managing risk lies with the executive, prior to review by the Trustees.

A summary extract of the higher risks from DEBRA's risk register are listed in Table 3 below, including the countermeasures (actions in place to reduce likelihood of the risk) and assurances (how the effectiveness of the countermeasures is determined). DEBRA as an organisation is very proactive in its management of risk, instilling a culture of recognition, ownership and tolerance level for each risk identified.

Table 3: Summary Extract from DEBRA's Risk Register

Identified Risk Factor	Countermeasure	Assurance
Charity image damaged	Marketing and PR strategy Disciplinary policy Crisis communication plan Review of any complaints received Extensive social media policy for staff	Media monitoring Annual staff appraisals Register of crises Investigation of occurrences
Insufficiently robust cyber security	Anti-virus software Cyber insurance policy Encryption of hard drives Secured wifi connection Offsite backup three times weekly Use of firewalls PCI compliance	Anti-virus tool displays Monthly reports Firewall logs checked regularly Daily logs of server activity
Misuse of data and failure to comply with Data Protection legislation	In-house Data Protection Officer Data protection policy Regular data protection training	Data protection working party Regular reporting
Loss of key staff and knowledge	Job and knowledge sharing Procedure documentation Succession planning Attractive terms of employment	Annual appraisals Exit interviews
Incompetent senior managers	Robust recruitment procedure Pre-employment references Induction and training	Performance against budget Annual appraisal and regular reviews Staff satisfaction survey
Loss of major source of fundraising income	Diversity of fundraising activities Regular contact with supporters	Quarterly fundraising and communications meetings with trustees Performance against budget
Decline in retail contribution	Monthly detailed shops reporting Separate retail risk register Continuous drive to grow contribution	Quarterly Retail Committee meetings with trustees Performance against budget
Failure to ensure safeguarding of vulnerable adults and children	In-house Safeguarding Officer Staff training	Activity reports Register of complaints and incidents

STRUCTURE, GOVERNANCE AND MANAGEMENT

DEBRA (a Company Limited by Guarantee) is a membership organisation and governed by its Articles of Association, which state that the Board shall comprise of up to 15 Trustees, with no less than 50% of the members having direct experience of EB.

DEBRA TRUSTEES

DEBRA members elect up to the majority of eight of the Trustees and the Nominations and Governance Committee is responsible for proposing up to a further seven with relevant skills to be appointed by the Trustees themselves.

At the Annual General Meeting in 2017, Simon Cuzner was re-appointed and Warren Alexander was appointed, as recommended by the Nominations & Governance Committee, and four additional candidates were elected (two re-elected and two new) by the members leaving a casual vacancy for an appointed Trustee. Subsequently, Warren Alexander resigned in July 2017, meaning DEBRA had 13 trustees on the Board as at 31 December 2017.

New Trustees receive a Trustee Handbook and other relevant publications, individual inductions from senior staff and trustee training as required. There are four board meetings per year, which the CEO and Senior Management Team (SMT) attend. At the end of 2017, an external governance review of the Board and Committee effectiveness was carried out and the Board will review recommendations from the report in 2018.

TRUSTEE COMMITTEES

Finance, Risk and Audit Committee – determines and advises the Trustee Board on matters relating to finance, risk and audit as the Trustee Board may remit to it, in particular the sound financial management of the charity, its resources, and assets.

Nominations and Governance Committee – oversees the structure, composition and effectiveness of the charity's Board of Trustees and its Committees, as well as the appointment process of Trustees. The Committee monitors the governance procedures of the charity.

Charitable Activities Committee – determines and advises the Trustee Board on matters relating to strategy in research, healthcare, community support and policy as the Trustee Board may remit to it.

Retail Committee – determines and advises the SMT and the Board of Trustees on matters relating to the shops. It utilises specific knowledge of its members to assist the CEO and Director of Retail to manage the shops, deliver operational performance against plan, comply with regulations and promote the cause of the charity.

Fundraising and Communications Committee – oversees the fundraising activities of the SMT on matters relating to the growth of income generation and maximising opportunities within Marketing and PR. The Committee approves and recommends to the Board of Trustees the strategic direction of fundraising and the financial plan. It utilises specific knowledge of its members to challenge and support the Director of Fundraising and Communications and the Marketing and PR management team to deliver against plans, comply with regulations and promote the cause of the charity.

DEBRA UK International Committee – determines and advises the Trustee Board on matters relating to international strategy in research, healthcare, community support and international policy as the Trustee Board may remit to it.

In addition, the international Medical and Scientific Advisory Panel makes recommendations for research projects.

Table 4: Trustees' Membership and Attendance Records

Board of Trustees			Committees					
Trustee	Year of Appointment	Board Meetings	Finance, Risk & Audit	Nominations & Governance	Charitable Activities	Retail	Fundraising & Communications	DEBRA UK International
David Spence - Chair	2009	4 of 4	4 of 4	3 of 4	-	4 of 5	-	-
Michael Jaega - Vice Chair	2013	4 of 4	3 of 4	4 of 4	4 of 4	-	-	3 of 3
James Irvine - Treasurer	2012	2 of 4	4 of 4	-	-	4 of 5	-	-
Warren Alexander	2017	0	-	-	-	-	-	-
Simone Bunting	2011	3 of 4	-	2 of 4	-	-	3 of 3	-
Rebecca Cresswell	2017	2 of 2	-	-	-	-	1 of 3	-
Simon Cuzner	2014	4 of 4	1 of 1	-	-	5 of 5	-	-
Rhian Edwards	2015	0	-	-	-	-	-	-
Andrew Grist	2016	4 of 4	-	-	3 of 4	-	-	2 of 3
James Hinchcliffe	2011	3 of 4	1 of 4	-	-	-	-	-
Graham Marsden	2012	3 of 4	-	4 of 4	-	-	-	3 of 3
Joanne Merchant	2015	4 of 4	4 of 4	-	-	-	-	3 of 3
Vivien Mundy	2017	2 of 2	-	-	2 of 2	-	-	-
Scott O'Sullivan	2014	0	-	-	-	-	-	-
John Parker	2016	1 of 1	-	-	-	-	1 of 3	-
Timothy Powell	2015	2 of 4	-	-	0 of 4	-	-	-
David Wilkinson	2016	3 of 4	-	-	-	-	2 of 3	-

*Records in **bold** indicates Committee Chair

SUCCESSION PLANNING

DEBRA has built strength and depth in its trustee board, incorporating appropriate succession planning. The post of Chair of Trustee Board, following the upcoming retirement of David Spence at the AGM in May 2018, after 9 devoted years as a trustee, will be ably filled by Michael Jaega. There has been a well thought through handover period.

STRUCTURE, GOVERNANCE AND MANAGEMENT

FUNDRAISING STANDARDS

Section 162a of the Charities Act 2011 requires charities to make a statement regarding fundraising activities. DEBRA does not undertake face to face fundraising from the general public. The legislation defines fundraising as 'soliciting or otherwise procuring money or other property for charitable purposes'. Such amounts receivable are presented in the accounts as 'voluntary income' and include legacies and grants. DEBRA makes all efforts to train staff and ensure compliance to fundraising standards at all times. Specifically:

- The majority of solicitations are managed internally, without involvement of professional fundraisers. The day-to-day management of all income generation is delegated to the executive team, who are accountable to the Trustees.
- Where DEBRA works with third parties collaboratively on events or other activities, the charity has a contract in place to ensure standards are met.
- There are documented procedures in place for the management of fundraising products – such as collection boxes, public collections, online fundraising sites, etc.
- Where volunteers assist in DEBRA's fundraising activities, they are briefed verbally and/or in writing on the process and best practices and two-way partnerships are issued.
- Volunteer fundraisers are managed and supported from the offices in Crowthorne and Blantyre. Their progress is closely tracked, and they are advised of the standards expected of them.
- Data protection procedures are in place governing the management of supporter and donor data on DEBRA's database; steps are underway to ensure compliance with the GDPR rules that come into force in May 2018.
- DEBRA does work with vulnerable people, particularly within the EB Community, and often they do wish to get involved with fundraising. There is close liaison between Fundraising and the Community Support Teams to identify any potential risks and act accordingly.
- DEBRA is a member of the Fundraising Regulator and complies with the relevant codes of practice.
- DEBRA received 7 fundraising complaints in 2017, all of which were registered, satisfactorily resolved and recorded.
- DEBRA received 26 compliments in 2017 for either the service they provide to the EB Community or through liaising with the general public in DEBRA shops.

ACTIVITIES IN SCOTLAND

DEBRA is active across several areas in Scotland. The primary charitable activities are seen in funding community support and research projects, notably at the Universities of Dundee and Edinburgh.

On the income generation side, there were two regional fundraising members of staff and 39 charity shops, both supported by an active volunteer network. The retail administration office for the entire charity is based in Blantyre.

AUDITORS

The Trustees on the Finance, Risk and Audit Committee, on behalf of all Trustees, have taken all reasonable steps to make themselves aware of any information needed by the company's auditors for the purposes of their audit and to establish that the auditors are aware of that information. The Trustees are not aware of any relevant audit information of which the auditors are unaware.

BDO LLP have expressed their willingness to continue in office. Under the Companies Act 2006 section 487(2) they will be automatically re-appointed as auditors 28 days after these accounts are sent to the members, unless the members exercise their rights under the Companies Act 2006 to prevent their re-appointment.

The Trustees' Annual Report, incorporating the Strategic Report, is approved by the Board of Trustees and signed on behalf of the Trustees:

David Spence
Chair of Trustees

26 April 2018



TRUSTEES' STATEMENT OF RESPONSIBILITIES

The Trustees are responsible for preparing the Strategic Report, the Trustees' Annual Report and the Financial Statements in accordance with applicable law and regulations.

Company law requires the Trustees to prepare financial statements for each financial year in accordance with United Kingdom Generally Accepted Accounting Practice (United Kingdom Accounting Standards and applicable law). Under company law the Trustees must not approve the financial statements unless they are satisfied that they give a true and fair view of the state of affairs of the charity and of the incoming resources and application of resources, including the income and expenditure, of the charity for that period.

In preparing these financial statements, the Trustees are required to:

- Select suitable accounting policies and then apply them consistently
- Make judgements and accounting estimates that are reasonably prudent
- State whether applicable UK Accounting Standards have been followed, subject to any material departures disclosed and explained in the financial statements
- Prepare the financial statements on the going concern basis unless it is inappropriate to presume that the charity will continue in business

The Trustees are responsible for keeping adequate accounting records that are sufficient to show and explain the charity's transactions and disclose with reasonable accuracy at any time the financial position of the charity and enable them to ensure that the financial statements comply with the Companies Act 2006. They are also responsible for safeguarding the assets of the charity and hence for taking reasonable steps for the prevention and detection of fraud and other irregularities.

Financial statements are published on the charity's website in accordance with legislation in the United Kingdom governing the preparation and dissemination of financial statements, which may vary from legislation in other jurisdictions. The maintenance and integrity of the charity's website is the responsibility of the Trustees. The Trustees' responsibility also extends to the on-going integrity of the financial statements contained therein.

AUDITOR'S REPORT

INDEPENDENT AUDITOR'S REPORT TO THE MEMBERS AND TRUSTEES OF DEBRA

OPINION

We have audited the financial statements of Debra ('the Charitable Company') for the year ended 31 December 2017 which comprise the statement of financial activities, the balance sheet, the cash flow statement and notes to the financial statements, including a summary of significant accounting policies. The financial reporting framework that has been applied in their preparation is applicable law and United Kingdom Accounting Standards, including Financial Reporting Standard 102 The Financial Reporting Standard applicable in the UK and Republic of Ireland (United Kingdom Generally Accepted Accounting Practice).

In our opinion, the financial statements:

- give a true and fair view of the state of the Charitable Company's affairs as at 31 December 2017 and of its incoming resources and application of resources for the year then ended;
- have been properly prepared in accordance with United Kingdom Generally Accepted Accounting Practice; and
- have been prepared in accordance with the requirements of the Companies Act 2006, the Charities and Trustee Investment (Scotland) Act 2005 and regulation 8 of the Charities Accounts (Scotland) Regulations 2006, as amended in 2010.

BASIS FOR OPINION

We conducted our audit in accordance with International Standards on Auditing (UK) (ISAs (UK)) and applicable law. Our responsibilities under those standards are further described in the Auditor's responsibilities for the audit of the financial statements section of our report. We are independent of the Charitable Company in accordance with the ethical requirements relevant to our audit of the financial statements in the UK, including the FRC's Ethical Standard, and we have fulfilled our other ethical responsibilities in accordance with these requirements. We believe that the audit evidence we have obtained is sufficient and appropriate to provide a basis for our opinion.

CONCLUSIONS RELATED TO GOING CONCERN

We have nothing to report in respect of the following matters in relation to which the ISAs (UK) require us to report to you where:

- the Trustees' use of the going concern basis of accounting in the preparation of the financial statements is not appropriate; or
- the Trustees have not disclosed in the financial statements any identified material uncertainties that may cast significant doubt about the Charitable Company's ability to continue to adopt the going concern basis of accounting for a period of at least twelve months from the date when the financial statements are authorised for issue.

AUDITOR'S REPORT

OTHER INFORMATION

The other information comprises the information included in the Annual Report, other than the financial statements and our auditor's report thereon. The other information comprises: the Chairman and CEO statement and the Strategic Report. The Trustees are responsible for the other information.

Our opinion on the financial statements does not cover the other information and, except to the extent otherwise explicitly stated in our report, we do not express any form of assurance conclusion thereon.

In connection with our audit of the financial statements, our responsibility is to read the other information and, in doing so, consider whether the other information is materially inconsistent with the financial statements or our knowledge obtained in the audit or otherwise appears to be materially misstated. If we identify such material inconsistencies or apparent material misstatements, we are required to determine whether there is a material misstatement in the financial statements or a material misstatement of the other information. If, based on the work we have performed, we conclude that there is a material misstatement of this other information, we are required to report that fact.

We have nothing to report in this regard.

OPINIONS ON OTHER MATTERS PRESCRIBED BY THE COMPANIES ACT 2006

In our opinion, based on the work undertaken in the course of the audit:

- the information given in the Trustees' Report, which includes the Directors' Report and the Strategic report prepared for the purposes of Company Law, for the financial year for which the financial statements are prepared is consistent with the financial statements; and
- the Strategic report and the Directors' Report, which are included in the Trustees' Report, have been prepared in accordance with applicable legal requirements.

MATTERS ON WHICH WE ARE REQUIRED TO REPORT BY EXCEPTION

In the light of the knowledge and understanding of the Charitable Company and its environment obtained in the course of the audit, we have not identified material misstatement in the Strategic report or the Trustee's report.

We have nothing to report in respect of the following matters in relation to which the Companies Act 2006 and the Charities and Trustee Investment (Scotland) Act 2005 requires us to report to you if, in our opinion:

- proper and adequate accounting records have not been kept, or returns adequate for our audit have not been received from branches not visited by us; or
- the financial statements are not in agreement with the accounting records and returns; or
- certain disclosures of Directors' remuneration specified by law are not made; or
- we have not received all the information and explanations we require for our audit.

RESPONSIBILITIES OF TRUSTEES

As explained more fully in the Trustees' statement of responsibilities, the Trustees (who are also the directors of the charitable company for the purposes of company law) are responsible for the preparation of the financial statements and for being satisfied that they give a true and fair view, and for such internal control as the Trustees determines is necessary to enable the preparation of financial statements that are free from material misstatement, whether due to fraud or error.

In preparing the financial statements, the Trustees are responsible for assessing the Charitable Company's ability to continue as a going concern, disclosing, as applicable, matters related to going concern and using the going concern basis of accounting unless the Trustees either intend to liquidate the Charitable Company or to cease operations, or have no realistic alternative but to do so.

AUDITOR'S RESPONSIBILITIES FOR THE AUDIT OF THE FINANCIAL STATEMENTS

We have been appointed as auditor under section 44(1)(c) of the Charities and Trustee Investment (Scotland) Act 2005 and under the Companies Act 2006 and report in accordance with the Acts and relevant regulations made or having effect thereunder.

This report is made solely to the Charitable Company's members, as a body, in accordance with Chapter 3 of Part 16 of the Companies Act 2006, and to the Charitable Company's trustees, as a body, in accordance with the Charities and Trustee Investment (Scotland) Act 2005. Our audit work has been undertaken so that we might state to the Charitable Company's members and trustees those matters we are required to state to them in an auditor's report and for no other purpose. To the fullest extent permitted by law, we do not accept or assume responsibility to anyone other than the Charitable Company, the Charitable Company's members as a body and the Charitable Company's trustees as a body, for our audit work, for this report, or for the opinions we have formed.

Our objectives are to obtain reasonable assurance about whether the financial statements as a whole are free from material misstatement, whether due to fraud or error, and to issue an auditor's report that includes our opinion. Reasonable assurance is a high level of assurance, but is not a guarantee that an audit conducted in accordance with ISAs (UK) will always detect a material misstatement when it exists. Misstatements can arise from fraud or error and are considered material if, individually or in the aggregate, they could reasonably be expected to influence the economic decisions of users taken on the basis of these financial statements.

A further description of our responsibilities for the audit of the financial statements is located at the Financial Reporting Council's ('FRC's') website at: <https://www.frc.org.uk/auditorsresponsibilities>. This description forms part of our auditor's report.

Julia Poulter (Senior Statutory Auditor)

For and on behalf of BDO LLP, statutory auditor

Gatwick, West Sussex

Date:

BDO LLP is a limited liability partnership registered in England and Wales (with registered number OC305127).



Mason's Story

Campaigning for inclusion...

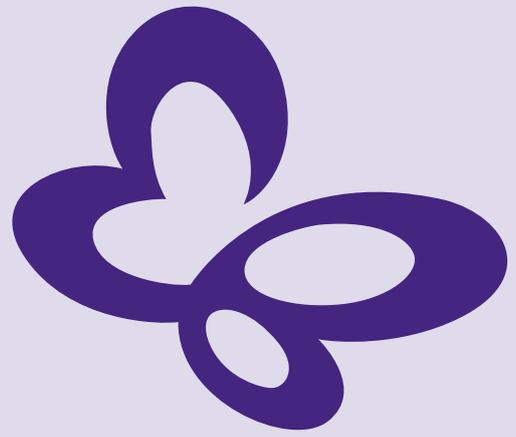
'Having to keep a smile on your face day after day while living a life full of pain.' Sadly, Mason's parents know all too well what that's like. Mason, 9, loves going to school. He's ahead of his age in reading and top of the class in maths. Even though he is in constant pain, nothing gets in the way of his learning.

His parents feared this would never happen. Mason suffers from EB and his skin blisters and tears at the slightest touch. 'Even the thought of sending him to school was an absolute nightmare,' says his mum, Kerry. 'The slightest knock or rub could tear his skin off, so the thought of his facing a crowded corridor or being jostled in the playground really did terrify us.'

With information and support from DEBRA, they worked with the school to make sure he's included as much as possible. He sits on a sheepskin lining to protect his fragile skin. He also uses a mobility scooter to stay active during the lunchbreak and minimise blistering on his feet. But he still needs round the clock care.

Mason's future remains uncertain. He's had over thirteen operations to deal with problems caused by his EB. He has to be fed through a tube. He's very vulnerable to serious infections. And it's highly likely he'll need more surgery in future.

'The hardest thing about EB is not knowing what the future holds. Mason's very bright - we can't fool him about what he might have to face as he gets older,' says Kerry.



FINANCIAL STATEMENTS

For the year ended
31 December 2017

STATEMENT OF FINANCIAL ACTIVITIES

STATEMENT OF FINANCIAL ACTIVITIES INCLUDING INCOME AND EXPENDITURE ACCOUNT FOR THE YEAR ENDED 31 DECEMBER 2017

		2017 Unrestricted funds	2017 Designated funds	2017 Restricted funds	2017 Total	2016 Unrestricted funds	2016 Designated funds	2016 Restricted funds	2016 Total
Notes	£	£	£	£	£	£	£	£	£
INCOME AND ENDOWMENTS FROM:									
Donations and legacies	2	2,985,017	-	376,384	3,361,401	2,181,611	65,125	333,360	2,580,096
Charitable activities		17,150	-	-	17,150	14,483	-	-	14,483
Other trading activities	3	10,110,557	2,429,929	173,967	12,714,453	8,833,920	2,374,029	96,231	11,304,180
Investments	4	40,253	-	-	40,253	39,587	-	-	39,587
Other		48,985	-	-	48,985	197,997	-	-	197,997
Total		13,201,962	2,429,929	550,351	16,182,242	11,267,598	2,439,154	429,591	14,136,343
EXPENDITURE ON:									
Raising funds	6	11,154,010	2,027,970	-	13,181,980	9,614,405	2,179,261	-	11,793,666
Charitable activities	6	957,471	1,796,593	545,428	3,299,492	863,367	501,870	349,524	1,714,761
Total		12,111,481	3,824,563	545,428	16,481,472	10,477,772	2,681,131	349,524	13,508,427
Net income/ (expenditure)		1,090,481	(1,394,634)	4,923	(299,230)	789,826	(241,977)	80,067	627,916
Transfer between funds		(1,067,617)	1,067,617	-	-	(827,288)	848,588	(21,300)	-
Net movement in funds		22,864	(327,017)	4,923	(299,230)	(37,462)	606,611	58,767	627,916
Reconciliation of funds:									
Total funds brought forward		2,026,226	2,274,803	75,553	4,376,582	2,063,688	1,668,192	16,786	3,748,666
Total funds carried forward		2,049,090	1,947,786	80,476	4,077,352	2,026,226	2,274,803	75,553	4,376,582

All operations are continuing. The Statement of Financial Activities also complies with the requirements for an income and expenditure account under the Companies Act 2006.

The notes on pages 55 to 70 form part of these financial statements.

BALANCE SHEET

BALANCE SHEET AS AT 31 DECEMBER 2017

Company registration number: 4118259

		2017		2016	
	Notes	£	£	£	£
Fixed assets					
Tangible assets	10		1,157,053		1,249,228
Investment in DEBRA Trading Ltd	21		2		2
			1,157,055		1,249,230
Current assets					
Current asset investment	11	1,800,000		1,400,000	
Stocks		19,260		25,066	
Debtors	12	1,542,974		1,568,698	
Cash at bank and in hand		3,207,830		3,099,431	
		6,570,064		6,093,195	
Creditors: Amounts falling due within one year:	13	(2,619,271)		(2,753,384)	
Net current assets			3,950,793		3,339,811
Total assets less current liabilities			5,107,848		4,589,041
Creditors: Amounts falling due over one year:	13		(820,496)		(32,459)
Provisions for liabilities	13		(210,000)		(180,000)
Total net assets			4,077,352		4,376,582
The funds of the charity					
Restricted income funds	15		80,476		75,553
Unrestricted funds	15		3,996,876		4,301,029
			4,077,352		4,376,582

The notes on pages 55 to 70 form part of these financial statements.

The accounts were approved by the Board on 26 April 2018 and signed on their behalf by:

David Spence
Chair of Trustees

James Irvine
Treasurer

CASH FLOW STATEMENT

CASH FLOW STATEMENT FOR THE YEAR ENDED 31 DECEMBER 2017

		2017		2016	
	Notes	£	£	£	£
CASH FLOWS FROM OPERATING ACTIVITIES:					
Net cash provided by operating activities	17		491,664		57,433
CASH FLOWS FROM INVESTING ACTIVITIES:					
Dividends, interest and rents from investments		40,253		39,587	
Proceeds from the sale of property, plant and equipment		221,550		350,001	
Purchase of property, plant and equipment		(245,068)		(55,985)	
Net cash provided by investing activities			16,735		333,603
Change in cash and cash equivalents in the reporting period			508,399		391,036
Cash and cash equivalents at the beginning of the reporting period			4,499,431		4,108,395
Cash and cash equivalents at the end of the reporting period			5,007,830		4,499,431

The notes on pages 55 to 70 form part of these financial statements.

NOTES TO THE ACCOUNTS

1. ACCOUNTING POLICIES

Basis of Preparation

The financial statements have been prepared in accordance with Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) (effective 1 January 2015), Charities SORP (FRS 102), the Companies Act 2006, the Charities Accounts (Scotland) Regulations 2006 as amended and the Charities and Trustees Investment (Scotland) Act 2005.

Going Concern

The trustees conclude that the charity is a going concern because of the continuing financial strength of the balance sheet underpinned by a robust reserves policy, and the anticipated on-going income streams generated by fundraising and retail activities.

Legal Status of Charity

The charity is a company limited by Guarantee and has no share capital. In the event of the charity being wound up, the liability in respect of the guarantee is limited to £1 per member of the charity.

Incoming Resources

General donations and trading income are recognised in full in the statement of financial activities when received. Legacies and grants receivable are recognised when the amount due is probable. Income is deferred where it represents a payment in advance for a specific event that will not take place until a future accounting period, except for sponsorship for charity challenges. Gifts in kind are only included in the accounts where the trustees can ascribe a value in excess of £1,000.

Resources Expended

Expenditure is accounted for on an accruals basis where practicable to do so, and has been classified under headings that aggregate all costs related to the category. Equipment purchased for use in research is written off as part of the research project costs as incurred. Expenditure on raising funds are those costs incurred in seeking voluntary contributions and running the retail operations. Charitable activities include expenditure associated with the operation of the charity and the provision of its services. Governance costs comprise the costs relating to the general running of the charity, and include direct items such as external audit, legal advice for trustees, the cost of trustee meetings, and are included in central overhead costs. Central costs are apportioned and allocated between the costs of generating funds and charitable expenditure on the basis of central staff time allocation to the various activities.

Recognition of Grant Liabilities

Grants are awarded for research projects over a period of one to five years. All grants provide the right to terminate with three months notice and continuation of funding is dependent on satisfactory progress reporting and review. Full grant recognition has been incorporated into these accounts as the most prudent policy.

NOTES TO THE ACCOUNTS

ACCOUNTING POLICIES (CONTINUED)

Tangible Fixed Assets and Depreciation

Tangible fixed assets with a value in excess of £1,000 are capitalised and stated at cost less depreciation. Depreciation is provided at rates calculated to write off the cost less estimated residual value of each asset over its expected useful life, as follows:

Freehold and long leasehold land and buildings	Over 25 years
Mobile homes	Over 10 years
Fixtures, fittings, static equipment	Over 5 years
Shop tills	Over 5 years
Motor vehicles	Over 4 years
Mobile equipment	Over 3 years

A review of assets is undertaken annually, and adjustments are made to the expected useful life as required. From 1 January 2009 freehold land and buildings are assumed to have a residual value of 50%.

Intangible Fixed Assets and Amortisation

The charity acquired ten freehold properties from another charity in September 2009. The difference between the market value and the price paid is recognised as negative goodwill. This is amortised in line with a reducing guarantor liability on the assets, which commenced in 2010 and ran for six years.

Sale and Leaseback

Where a sale and leaseback transaction results in an operating lease, and it is clear that the transaction is established at fair value, any profit or loss is recognised immediately. If the sale price is below fair value, any profit or loss is recognised immediately unless the loss is compensated for by future lease payments at below market price. In that case any such loss is amortised in proportion to the lease payments over the period for which the asset is expected to be used. If the sale price is above fair value, the excess over fair value is amortised over the period for which the asset is expected to be used.

Cash and Short-Term Investments

The charity holds cash requirements for day-to-day activities in current bank accounts with HSBC, Lloyds, Santander and Clydesdale. The deposit account is held with HSBC. Short-term investments are held in money market deposits with Lloyds Commercial Banking. For the purposes of the cash flow statement, cash equivalents are defined as current asset investments, and short-term deposits, which are readily convertible into known amounts of cash.

Debtors

Trade and other debtors are recognised at the settlement amount due after any trade discount offered. Prepayments are valued at the amount prepaid net of any trade discounts due.

Creditors

Trade creditors and other payables are normally recognised at their settlement amount after allowing for any trade discount due. Payments to suppliers are within standard payment terms of 30 days. Liabilities are recognised when there is a present obligation, as a result of past events, and there is a probable future outflow of resources that can be estimated reliably.

Financial Instruments

The charity only has financial assets and financial liabilities of a kind that qualify as basic financial instruments. Basic financial instruments are initially recognised at transaction value and subsequently measured at settlement value.

Stock

The trustees do not consider it appropriate to recognise donated goods for resale as stock on the grounds that the cost of obtaining stock information would greatly outweigh any benefit. The costs involved would include the setting up of processes and procedures for a stock count in over 100 shops, training shop staff and volunteers in the process, software programming, and the checking and analysis of the reports produced.

All other stock is valued at the lower of cost or net realisable value.

Accumulated Funds

Restricted funds are subject to specific conditions by donors as to how they may be used. Transfers between unrestricted funds and designated funds occur when the trustees approve either funds to be designated for a specific purpose, or where remaining designated funds are no longer required and are released to unrestricted funds. The purposes and uses of the restricted funds and designated funds are set out in Note 15 to the financial statements.

Consolidated Accounts

The accounts of DEBRA Trading Limited and DEBRA Retail Limited have not been incorporated into these accounts on the grounds that the results are not material. The profit covenanted by DEBRA Trading Limited is included in other trading activities. DEBRA Retail Limited was dormant throughout the year. This report therefore provides information about the standalone charity only. For information, the company's results and the investment the charity holds in DEBRA Trading Limited are shown separately in note 21 to the financial statements.

Foreign Currency Translation

Foreign currency transactions are recorded at the exchange rate at the time of the transaction. Foreign currency assets and liabilities are translated into sterling at the exchange rate ruling at the balance sheet date. Resulting gains or losses on retranslation are included in the statement of financial activities.

Leases

Operating lease annual rental payments are charged to the Statement of Financial Activities (SOFA) on a straight-line basis over the term of the lease.

Judgments and Estimates Made by Management

Legacy income is recognised as probable at probate. Premises service charge liabilities are estimated from information supplied by property specialists. The dilapidations provision is reviewed annually on an individual lease basis by a property specialist. As noted in the going concern policy above, the trustees consider the charity is a going concern because financial strength is maintained. The trustees do not consider that there are any sources of estimation uncertainty at the reporting date that have a significant risk of causing a material adjustment to the carrying amounts of assets and liabilities within the next reporting period.

Termination Payments

Termination payments either by way of redundancy, settlement agreement or 'gardening leave' are recognised at the time of payment. Any payments exceeding the statutory minimum are authorised by the trustees.

NOTES TO THE ACCOUNTS

2. DONATIONS AND LEGACIES

	Unrestricted Funds	Restricted Funds	Total 2017	Total 2016
	£	£	£	£
Donations & gifts	2,661,329	60,865	2,722,194	2,270,501
Legacies receivable	281,476	200	281,676	67,226
Grants receivable	42,212	315,319	357,531	242,369
	2,985,017	376,384	3,361,401	2,580,096
Donations & gifts:				
Individual donations	1,874,789	49,434	1,924,223	1,941,669
Corporate donations	699,139	11,191	710,330	232,188
International donations	602	-	602	1,090
Events by individuals	86,799	240	87,039	95,554
	2,661,329	60,865	2,722,194	2,270,501
Grants receivable:				
Charitable trusts	42,212	315,319	357,531	242,369
	42,212	315,319	357,531	242,369

Gifts in kind of £430,000 (2016: £49,300) are included in donations and gifts. These include the production of animated videos valued at £150,000 (2016: £0) and on-going advertising in a national newspaper valued at £147,072 (2016: £20,800).

3. OTHER TRADING ACTIVITIES

	Total 2017	Total 2016
	£	£
Income	12,714,453	11,304,180
Operating expenses	(12,098,920)	(10,974,267)
Net income from fundraising activities	615,533	329,913

The greatest income from other trading activities is derived from the operation of charity shops selling donated goods. As at 31 December 2017 there were 131 shops trading (2016:130). The major categories of income and expenditure are summarised below:

	Income	Operating Expense	Total 2017	Total 2016
	£	£	£	£
Retail	11,801,915	(11,489,820)	312,095	84,029
Fundraising events	812,951	(609,014)	203,937	179,592
Miscellaneous trading	99,587	(86)	99,501	66,292
	12,714,453	(12,098,920)	615,533	329,913

The net income incurred by retail excludes £1,257,562 (2016: £1,187,243) from retail Gift Aid and retail donations, which are recognised as donations on the SOFA and not income from other trading activities. There was significant investment in retail during 2016 in new shop openings, where set up costs were written off as incurred and not depreciated over the life of the lease. In 2017 there was strong like for like growth in retail and a slow down in new shop openings. The profit covenanted by DEBRA Trading Limited of £15,860 (2016: £15,703) is included in miscellaneous trading.

Total retail income, including retail Gift Aid and retail donations, was as follows:

	Total 2017	Total 2016
	£	£
Retail income	13,059,477	11,658,542
Retail expenditure	(11,489,820)	(10,387,270)
Retail net income	1,569,657	1,271,272

4. INVESTMENTS

	Unrestricted Funds	Total 2017	Total 2016
	£	£	£
Interest receivable	15,240	15,240	16,082
Rent of property	25,013	25,013	23,505
Total investment income	40,253	40,253	39,587

Rental income was received from one freehold shop and two flats situated above properties, which were acquired in 2009.

5. GRANTS PAYABLE

Expenditure on charitable activities includes grants payable to third parties as detailed in Note 20. There were 233 Community Support grants totalling £63,369 made through the Community Support programme. All other grants were payable to institutions as detailed in Note 20.

Routine Healthcare and Community Support work is considered on-going and for which no future commitment is provided. Research and clinical projects have a finite life and at 31 December 2017 the Trustees had authorised a commitment to support research grants over the next three years to the sum of £1,218,000 (2016: £381,145) and clinical projects to the sum of £141,666 (2016: £0).

The total commitment is currently budgeted to be spent as follows:

	Total 2017	Total 2016
	£	£
Within 1 year	539,170	348,686
Within 2-3 years	820,496	32,459
	1,359,666	381,145
Provided within the grants payable creditor	1,359,666	381,145

NOTES TO THE ACCOUNTS

6. EXPENDITURE

	Staff Costs	Grants Payable	Other Costs	Total 2017	Total 2016
	£	£	£	£	£
Raising funds:	387,922	-	695,138	1,083,060	819,399
Voluntary income	5,676,642	-	6,422,278	12,098,920	10,974,267
Other trading activities	6,064,564	-	7,117,416	13,181,980	11,793,666
Charitable activities:	259,952	1,274,736	26,019	1,560,707	508,620
Research	150,033	539,640	25,382	715,055	267,198
Healthcare	599,738	63,369	44,289	707,396	628,576
Community support	-	-	64,626	64,626	62,069
Respite breaks	176,629	-	75,079	251,708	248,298
Public education	1,186,352	1,877,745	235,395	3,299,492	1,714,761
	7,250,916	1,877,745	7,352,811	16,481,472	13,508,427

Other costs

	Depreciation & Amortisation	Overhead Allocation	Miscellaneous Costs	Total 2017	Total 2016
	£	£	£	£	£
Raising funds:	-	164,894	530,244	695,138	338,187
Voluntary income	79,198	233,503	6,109,577	6,422,278	5,593,920
Other trading activities	79,198	398,397	6,639,821	7,117,416	5,932,107
Charitable activities:	-	26,019	-	26,019	29,219
Research	-	25,382	-	25,382	21,825
Healthcare	-	40,458	3,831	44,289	44,569
Community support	22,343	-	42,283	64,626	62,069
Respite breaks	-	75,079	-	75,079	71,570
Public education	22,343	166,938	46,114	235,395	229,252
	101,541	565,335	6,685,935	7,352,811	6,161,359

Net income/(expenditure) for the year is stated after charging:

	Total 2017	Total 2016
	£	£
Hire of plant and machinery – operating leases	30,815	29,834
Auditors remuneration	19,860	18,550
Non-audit services	11,326	15,174
Depreciation of tangible fixed assets	126,147	119,363
Defined contribution pension costs	233,133	234,116
Exchange differences	44,780	-

7. COST ALLOCATION

All central overhead costs are allocated to activities on the basis of staff time, and are detailed below:

	2017	2016
	£	£
Staff costs:	1,329,980	1,353,053
Overheads:		
Office premises rent	4,385	36,173
Service charges, utilities & cleaning	32,943	39,033
Equipment costs	142,972	141,468
Postage, printing, stationery, telephone & fax	84,386	88,702
Insurance costs	70,238	59,107
Legal, professional & consultancy fees	72,103	56,164
Depreciation	24,604	25,574
Irrecoverable VAT	46,141	40,976
Bank charges	8,622	10,987
Sundry expenses	52,611	24,067
Governance costs:		
Audit fees	19,860	18,550
Miscellaneous costs	6,470	7,142
	565,335	547,943
Total Allocation	1,895,315	1,900,996

Non-audit payments made to BDO totalled £11,326 in 2017 (2016: £15,174).

8. TRUSTEES

None of the trustees received any remuneration from DEBRA during the period, but 10 of them were reimbursed a total of £4,276 (2016: £5,443) for travel and subsistence expenses.

Rhian Edwards received community support grants in 2017 totalling £0 (2016: £25).

Michael Jaega received community support grants in 2017 totalling £637 (2016: £1,000).

Christo Kapourani received a community support grant of £0 (2016: £314).

Scott O'Sullivan received a community support grants in 2017 totalling £25 (2016: £0).

A close family member of a DEBRA trustee received a community support grant of £0 (2016: £25)

The aggregate figure for trustee donations in 2017 was £11,185 (2016: £11,970)

In addition many trustees have supported DEBRA by attending events.

Insurance has been purchased to protect DEBRA, its employees and trustees from professional and legal liability of trustees and employees in the event of a claim that arises from the actions of such persons acting in such capacity at a cost of £2,433 (2016: £2,379), as allowed under section 4.3.3 in DEBRA's Articles of Association.

NOTES TO THE ACCOUNTS

9. EMPLOYEES

The average number of employees during the period was:

	2017 Full Time Equivalent	2017 Number	2016 Number
Research	3.1	5	4
Healthcare*	1.0	1	1
Community Support	10.6	11	11
Fundraising	12.5	14	17
Retail	263.8	336	311
Management & Administration	12.7	16	16
	303.7	383	360

At the end of the year the number of employees per department was:

	2017 Full Time Equivalent	2017 Number	2016 Number
Research	3.1	5	5
Healthcare*	1.0	1	1
Community Support	12.5	13	11
Fundraising	12.1	13	16
Retail	259.3	335	322
Management & Administration	13.6	17	17
	301.6	384	372

*These numbers exclude healthcare staff funded through grants to external organisations as detailed in Note 20.

Staff employed by external institutions and funded through research grants are also excluded.

Employment Costs

	Total 2017	Total 2016
	£	£
Wages & salaries	6,061,935	5,840,791
Social security costs	401,912	385,086
Pension costs	233,133	234,116
	6,696,980	6,459,993

The charity does not operate any defined benefit pension scheme. The charity makes payments to certain employees' personal pension plans. Payments of £215,586 (2016: £242,303) were made in the year and charged to the SOFA in the period they were due. At the year end there remained £18,947 (2016: £1,400) unpaid.

There are adequate systems in place to manage expenses and they do not form part of remuneration.

The following members of staff received emoluments above £60,000:

	2017	2016
Between: £60,001 - £70,000	1	-
Between: £70,001 - £80,000	2	2
Between: £80,001 - £90,000	-	1
Between: £160,001 - £170,000	-	1
Between: £170,001 - £180,000	1	-

In respect of the above employees, contributions for the year into a defined contribution pension scheme totalled £48,438 (2015: £45,477), and there are retirement benefits accruing for four (2016: four) employees under a defined contribution scheme.

The aggregate pay of key management personnel, including employer's NI and pension contributions was £639,295 (2015: £676,360). The aggregate employer's pension contribution for key management personnel was £60,440 (2016: £61,472).

Redundancy and compensation payments totalled £14,400 in 2017 (2016: £68,984).

10. FIXED ASSETS

Tangible Fixed Assets

	Shop Fittings	Mobile Homes	Fixtures, Fittings & Equipment	Freehold Land & Buildings	Long Leasehold Land & Buildings	Total
	£	£	£	£	£	£
Cost:						
At 1 January 2017	336,957	256,687	203,164	1,122,461	82,500	2,001,769
Additions	89,287	134,965	20,816	-	-	245,068
Disposals	(67,336)	-	(24,246)	(323,114)	-	(414,696)
At 31 December 2017	358,908	391,652	199,734	799,347	82,500	1,832,141
Depreciation:						
At 1 January 2017	214,101	125,605	155,930	243,705	13,200	752,541
Charge for the year	60,251	22,343	17,667	24,236	1,650	126,147
Disposals	(67,336)	-	(24,013)	(112,251)	-	(203,600)
At 31 December 2017	207,016	147,948	149,584	155,690	14,850	675,088
Net Book Value:						
Brought forward	122,856	131,082	47,234	878,756	69,300	1,249,228
At 31 December 2017	151,892	243,704	50,150	643,657	67,650	1,157,053

NOTES TO THE ACCOUNTS

FIXED ASSETS (CONTINUED)

Intangible Fixed Assets

	Acquisition Goodwill
	£
Cost:	
At 1 January 2017 and 31 December 2017	(1,318,750)
Amortisation:	
At 1 January 2017 and 31 December 2017	1,318,750
Net Book Value:	
At 1 January 2017 and 31 December 2017	<u><u>-</u></u>

The charity acquired 10 freehold properties from Action for Children in September 2009, valued at £1,518,750. The difference between the market value and the price paid of £200,000 is recognised as negative goodwill. There has been a reducing balance guarantor liability on these assets restricting their sale.

The release of these assets from the restriction has been as follows:

Date	Released in Year	Cumulative
Mar 2010	115,000	115,000
Mar 2011	380,000	495,000
Mar 2012	290,000	785,000
Mar 2013	275,000	1,060,000
Mar 2014	193,750	1,253,750
Mar 2016	265,000	1,518,750

This negative goodwill was amortised in line with the reducing guarantor liability.

11. INVESTMENT IN SHORT TERM DEPOSITS

	2017	2016
	£	£
Lloyds money market deposits	1,800,000	1,400,000
	1,800,000	<u>1,400,000</u>

12. DEBTORS

	2017	2016
	£	£
HMRC	217,022	206,345
Miscellaneous debtors	18,849	51,183
Other debtors	10,023	7,458
Accrued income	654,036	752,818
Prepayments	643,044	550,894
	1,542,974	<u>1,568,698</u>

VAT repayment of £217,022 is due from HMRC. Accrued income includes gift aid of £306,050 due for 2017.

Total future minimum lease receivable was £24,111 in 2016 (2016: £31,981), in respect of one shop and two flats above shops.

13. CREDITORS

Amounts Falling Due Within One Year

	2017	2016
	£	£
Trade creditors	571,467	387,962
Grants payable	1,155,836	1,518,716
Other creditors	19,340	557
Taxation and social security	95,772	104,921
Accruals	743,666	717,078
Deferred income	33,190	24,150
	2,619,271	2,753,384

There was deferred income of £33,190 in the year (2016: £24,150), representing income for events which would have to be repaid in the event of cancellation.

Amounts Falling Due Over One Year

	2017	2016
	£	£
Grants payable	820,496	32,459
	820,496	32,459

There was a dilapidations provision of £210,000 (2016: £180,000). In the year £0 was released from the provision and a further £30,000 was charged. It is uncertain when this provision will be spent.

14. OTHER FINANCIAL COMMITMENTS

The following payments are committed to be paid in the future in respect of operating leases:

	2017	2016	2017	2016
	Leases of Land & Buildings	Leases of Land & Buildings	Other	Other
	£	£	£	£
Within 1 year	1,821,982	1,807,158	19,860	28,846
Within 2-5 years	1,545,206	2,005,421	36,358	10,111
After 5 years	-	10,134	-	952
	3,367,188	3,822,713	56,218	39,909

There were capital commitments of £8,301 at year end, falling due within one year (2016: £2,767).

NOTES TO THE ACCOUNTS

15. ANALYSIS OF FUNDS

Restricted Funds

	Balance at 31 Dec 2016	Income	Expenditure	Transfer to General Fund	Balance at 31 Dec 2017
	£	£	£	£	£
Research	24,531	220,831	(239,862)	-	5,500
Healthcare	34,728	251,233	(231,039)	-	54,922
Community Support & Respite	16,294	78,287	(74,527)	-	20,054
	75,553	550,351	(545,428)	-	80,476

	Balance at 31 Dec 2015	Income	Expenditure	Transfer to General Fund	Balance at 31 Dec 2016
	£	£	£	£	£
Research	980	145,618	(100,767)	(21,300)	24,531
Healthcare	6,972	51,081	(23,325)	-	34,728
Community Support & Respite	8,834	232,892	(225,432)	-	16,294
	16,786	429,591	(349,524)	(21,300)	75,553

Restricted Funds Comprise:

	2017	2016
	£	£
Research - Dundee project	5,500	-
Research - itch project	-	21,228
Research - clinical trials	-	1,974
Research - Cure EB (formerly 'Sohana Research Fund')	-	1,329
Healthcare - EB nurse leadership	45,409	-
Healthcare - GSTT Rare Diseases Centre	-	28,389
Healthcare - Birmingham Children's Hospital specialist bath	5,600	5,600
Healthcare - podiatry clinics	3,850	-
Healthcare - other restricted funds	63	724
Community Support - support grants in Northamptonshire	4,256	-
Community Support - support grants in Hampshire	3,164	3,164
Community Support - support grants in North West	-	2,249
Community Support - support grants in London	2,832	-
Community Support - holiday home	6,000	2,086
Community Support - other restricted funds	3,802	8,810
	80,476	75,553

Unrestricted Funds

The trustees have transferred the following amounts into designated funds during 2017:

	Balance at 31 Dec 2016	Transfers	Income	Expenditure	Balance at 31 Dec 2017
				£	£
Future research grants	1,031,906	1,904,910	-	(1,239,030)	1,697,786
Nursing continuity	491,073	201,365	-	(492,438)	200,000
Furniture and electrical shops	456,225	(858,184)	2,429,929	(2,027,970)	-
Special projects fund	230,474	(230,474)	-	-	-
GSTT Rare Diseases Centre	65,125	-	-	(65,125)	-
2020 EB conferences	-	50,000	-	-	50,000
Total designated funds	2,274,803	1,067,617	2,429,929	(3,824,563)	1,947,786
General fund	2,026,226	(1,067,617)	13,201,962	(12,111,481)	2,049,090
Total unrestricted funds	4,301,029	-	15,631,891	(15,936,044)	3,996,876

	Balance at 31 Dec 2015	Transfers	Income	Expenditure	Balance at 31 Dec 2016
	£	£	£	£	£
Future research grants	784,896	514,712	-	(267,702)	1,031,906
New health & community support projects	391,365	333,876	-	(234,168)	491,073
Furniture and electrical shops	491,931	-	2,143,555	(2,179,261)	456,225
Special projects fund	-	-	230,474	-	230,474
GSTT Rare Diseases Centre	-	-	65,125	-	65,125
Total designated funds	1,668,192	848,588	2,439,154	(2,681,131)	2,274,803
General fund	2,063,688	(827,288)	11,267,598	(10,477,772)	2,026,226
Total unrestricted funds	3,731,880	21,300	13,706,752	(13,158,903)	4,301,029

The funds held in excess of the minimum cash-backed reserves as stated in the Reserves Policy have been designated by the trustees to be expended on future research in line with the charitable objectives of the charity. There were transfers totalling £1,904,910 into this fund in 2017. It is anticipated this fund will be spent in the next 1-5 years.

The trustees designated £700,000 in 2011 to fund the set-up of a number of large Furniture and Electrical Shops. These shops are now generating a surplus so the purpose of this fund has been fulfilled. The trustees closed this fund and re-designated the balance to the designated fund for future research in 2017.

The designated fund for new health and community support projects was established in 2011 to demonstrate the trustees' commitment to ploughing back all savings from increased NHS funding of EB nurses into new health and community support projects. The trustees decided in 2017 to maintain a balance in this fund of £200k as a contingency in the event of future funding withdrawal, and to re-name the fund the nursing continuity designated fund.

The designated fund for special projects was established in 2016 following the increase in funds of £230,474 available for charitable spend from the disposal of two freehold assets. The trustees decided in 2017 to re-designate the balance in this fund to the designated fund for future research.

During 2016 the trustees designated £65,125 for the GSTT Rare Diseases Centre, following a successful fundraising lunch. This fund was spent in February 2017.

The trustees established a new designated fund for the 2020 EB conferences and decided to designate £50,000 to these conferences in 2017. It is anticipated a further £50,000 will be designated at the end of 2018, and the fund will be spent in the next 2-3 years.

NOTES TO THE ACCOUNTS

16. ANALYSIS OF NET ASSETS BETWEEN CATEGORIES OF FUNDS

	Unrestricted Funds	Restricted Funds	Total 2017	Total 2016
	£	£	£	£
Fund balances at 31 December 2017 are represented by:				
Fixed assets	1,157,055	-	1,157,055	1,249,230
Current assets	6,489,588	80,476	6,570,064	6,093,195
Creditors: amounts falling due within one year	(2,619,271)	-	(2,619,271)	(2,933,384)
Creditors: amounts falling due over one year	(1,030,496)	-	(1,030,496)	(32,459)
	<u>3,996,876</u>	<u>80,476</u>	<u>4,077,352</u>	<u>4,376,582</u>

	Unrestricted Funds	Restricted Funds	Total 2016	Total 2015
	£	£	£	£
Fund balances at 31 December 2016 are represented by:				
Fixed assets	1,249,230	-	1,249,230	1,258,193
Current assets	6,017,642	75,553	6,093,195	5,640,845
Creditors: amounts falling due within one year	(2,933,384)	-	(2,933,384)	(2,883,095)
Creditors: amounts falling due over one year	(32,459)	-	(32,459)	(267,277)
	<u>4,301,029</u>	<u>75,553</u>	<u>4,376,582</u>	<u>3,748,666</u>

17. RECONCILIATION OF NET INCOME (EXPENDITURE) TO NET CASH FLOW FROM OPERATING ACTIVITIES

	2017	2016
	£	£
Net income / (expenditure) for the reporting period (as per the statement of financial activities)	(299,230)	627,916
Depreciation and amortisation charges	126,147	(110,735)
Dividends, interest and rents from investments	(40,253)	(39,587)
Loss / (profit) on disposal of fixed assets	(10,454)	(174,319)
Decrease / (increase) in stock	5,806	(14,059)
Decrease / (Increase) in debtors	25,724	(47,255)
Increase / (decrease) in creditors	683,924	(184,528)
	<u>491,664</u>	<u>57,433</u>

18. RECONCILIATION OF NET CASH FLOW TO MOVEMENT IN NET FUNDS

	2017	2016
	£	£
Increase in cash	108,399	991,036
Cash outflow from increase in liquid resources	400,000	(600,000)
Net funds brought forward	4,499,431	4,108,395
Net funds carried forward	5,007,830	4,499,431

19. ANALYSIS OF CASH AND CASH EQUIVALENTS

	As at 1 Jan 2017	Cash Flows	As at 31 Dec 2017
	£	£	£
Cash at bank and in hand	3,099,431	108,399	3,207,830
Short term deposits	1,400,000	400,000	1,800,000
Total	4,499,431	508,399	5,007,830

20. GRANTS TO INSTITUTIONS

	Total 2017	Total to Date	Total Project Cost
	£	£	£
RESEARCH PROJECTS			
University of Dundee			
TGF β signalling in Recessive Dystrophic EB	68,164	166,240	190,284
Clinical fellow funding	89,868	202,081	202,081
EBS Genotyping	20,000	20,000	24,000
	178,032	388,321	416,365
University of Edinburgh			
Defining the role of Kindlin1	54,636	191,838	191,838
Guy's and St. Thomas' Hospital, London			
Validated clinical endpoints study re EB therapy evaluation	60,376	238,112	260,748
Study of lentiviral-mediated COL7A1, funded by Cure EB (formerly 'Sohana Research Fund')	68,474	494,905	499,320
Stem cell therapy trial to investigate treating debilitating itch	-	-	497,360
	128,850	733,017	1,257,428
Thomas Jefferson University, Philadelphia, USA			
Read-through of nonsense mutations in COL7A1	47,545	234,344	234,344
Phase 2 clinical trial of Rigosertib for RDEB SCC	101,234	101,234	462,830
	148,779	335,578	697,174

NOTES TO THE ACCOUNTS

GRANTS TO INSTITUTIONS (CONTINUED)

	Total 2017 £	Total to Date £	Total Project Cost £
RESEARCH PROJECTS			
Birmingham Dental School & Hospital			
Characterisation of skin microbiome in EB patients	-	-	296,289
Other			
Increase in research provision	836,854		
Grants written back at end of project	(72,414)		
Total research grants	1,274,737	1,648,754	2,859,094
Research project expenditure by category:			
Pre-clinical development	260,213		818,547
Genetic investigation	20,000		24,000
Clinical investigation	60,376		557,037
Patient treatment study	934,148		1,459,510
	1,274,737		2,859,094
HEALTHCARE PROJECTS			
Great Ormond Street Hospital for Sick Children			
Clinical nurse specialists in EB	34,327		37,397
Clinical best practice guidelines on hand therapy	26,930		26,930
Guy's & St. Thomas' Hospital London			
Contribution to Rare Diseases Centre	250,000		250,000
Adult EB support nurses	57,815		60,408
Other			
Podiatry service development	105,000		105,000
Birmingham Children's Hospital	33,936		35,766
Clinical best practice guidelines on podiatry	30,411		30,411
International projects	1,221		3,929
Miscellaneous	-		80,119
Total Healthcare Team grants	539,640		629,960

21. RELATED PARTIES

DEBRA Trading Ltd

The principal activity of DEBRA Trading Ltd (company number: 2487114), a company incorporated in England and Wales, is the sale of promotional items on behalf of DEBRA. DEBRA has a beneficial interest in 100% of the company's issued share capital of £2.

The company's results for the period under review were as follows:

	2017 £	2016 £
Turnover	46,020	36,087
Net profit gift aided to DEBRA	15,860	15,702
Net assets	2	2

During the year, the charity charged management charges totalling £6,933 including VAT (2016: (£5,182)) to its subsidiary, DEBRA Trading Limited.

REFERENCE AND ADMINISTRATIVE DETAILS

PATRONS AND AMBASSADORS

Royal Patron

HRH The Countess of Wessex

Life Patron

Philip Evans

Ambassadors

Scott O'Sullivan, Rhian Edwards

TRUSTEES

David Spence – Chair
Michael Jaega – Vice Chair
James Irvine – Treasurer
Warren Alexander (from 13 May – 3 July 2017)
Simone Bunting
Rebecca Cresswell (from 13 May 2017)
Simon Cuzner
Rhian Edwards (until 12 January 2017)
Andrew Grist

James Hinchcliffe
Graham Marsden
Joanne Merchant
Vivien Mundy (from 13 May 2017)
Scott O'Sullivan (until 12 January 2017)
John Parker (until 22 February 2017)
Timothy Powell
David Wilkinson

No trustee has any beneficial interest in the company. All trustees are members of the company and guarantee to contribute £1 in the event of a winding up.

SENIOR MANAGEMENT TEAM

Chief Executive

Ben Merrett

Director of Research

Caroline Collins

Director of Healthcare, Membership & Community Support

Claire Mather

Director of Retail

Paul Guest (until 25 July 2017)

Director of Fundraising & Communications

Hugh Thompson (from 27 March 2017)

Director of Human Resources

Louise Westphalen

Director of Finance

Carol Harris

Company Secretary

Dawn Jarvis

ADDITIONAL DETAILS

Charity Commission Number

1084958

OSCR Number

SC039654

Company Number

4118259

Registered office & principal address

DEBRA House, 13 Wellington Business Park
Dukes Ride, Crowthorne, Berks, RG45 6LS

Auditors

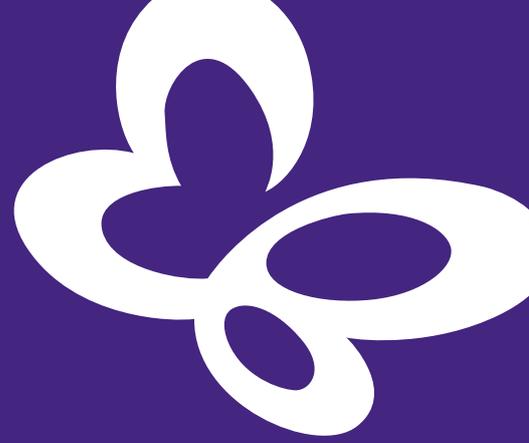
BDO LLP, 2 City Place, Beehive Ring Road
Gatwick, West Sussex, RH6 0PA

Bankers

HSBC, High Street
Crowthorne, Berks, RG45 7AD

Solicitors

Stone King, Boundary House
91 Charterhouse Street, London, EC1M 6HR



DEBRA provides lifelong care and support to the entire EB Community.

We make a difference today with the aim of a better future for those suffering from the condition.

Together, we #FightEB.

Facebook: /DEBRACHarity

Twitter: @charitydebra

Instagram: @charitydebra



Registered with
**FUNDRAISING
REGULATOR**

www.DEBRA.org.uk | 01344 771961 | debra@debra.org.uk

DEBRA House, 13 Wellington Business Park, Dukes Ride, Crowthorne, Berkshire, RG45 6LS

DEBRA | A charity registered in England and Wales (1084958) and Scotland (SC039654).
Company limited by guarantee registered in England (4118259). VAT Number 689 2482 79.